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EXPLORING THE EXPERIENCES OF LIVING WITH A CONTROVERSIAL
ILLNESS IN PATIENTS WITH FIBROMYALGIA

by

Samantha L. Wheeler

A Dissertation
Submitted to the
Faculty of the Graduate College
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Advisor: Dr. Alan Hovestadt, Ed.D.

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EXPLORING THE EXPERIENCES OF LIVING WITH A CONTROVERSIAL ILLNESS IN PATIENTS WITH FIBROMYALGIA

Samantha L. Wheeler

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Fibromyalgia is an illness of great controversy estimated to affect approximately 4% of the US population. There are no widely accepted etiological causes or clear physiological explanations of fibromyalgia. Only a few research studies have addressed the concept of illness uncertainty in patients with fibromyalgia. There are no current studies that examine how fibromyalgia patients experience, perceive, and understand their illness in terms of having a syndrome with an unknown etiology.

This qualitative study, using phenomenological methods, explored the concept of unknown etiology as one factor in illness uncertainty. Ten participants, diagnosed with fibromyalgia from 2-15 years were interviewed. The findings from the study are divided into two parts. The first part presents a description of each participant case along with each study participant's understanding of the cause of his or her illness. The second part of the findings offers the results from the data analyses at the cross case level and describes commonalities of the fibromyalgia illness experience.

The major findings of this study include the following: (a) common experiences of: pain, exhaustion, frustration, depression, cognitive difficulties, un-predictable and changing symptoms, not looking sick, and the experience of not being understood; (b) participants understood their illness as one that is invisible to others and one that is

constantly changing; (c) the unclear etiology had either a continuing negative impact or negative impact at the beginning of one's illness course, whereas those diagnosed longer let go of worry about cause and shifted to a coping focus; (d) friends were perceived to be more supportive than family or members of the medical community; (e) specialists in rheumatology and pain management were perceived as having the best response regarding members of the medical community; (f) the response from medical practitioners is improving; and (g) achieving support varied depending on the person considered.

Discussion of the study findings include relating the findings to existing research regarding fibromyalgia and illness uncertainty, implications of the findings for Counseling psychologists, and the strengths and limitations of the study. This study sought to provide helpful information through stories of fibromyalgia patients, with hope of contributing to the scarce body of knowledge regarding the subjective experiences of this controversial illness.

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CHAPTER I

INTRODUCTION

Fibromyalgia (FM) is an illness of great controversy that is estimated to affect approximately 4% of the US population, with that number increasing with age (Clauw & Crofford, 2003). According to Sinclair, Starz, and Turk (2005) FM is estimated to affect from 3 to 6 million people in the United States. The American College of Rheumatology (1990) defines fibromyalgia as a chronic disorder characterized by widespread musculoskeletal pain, fatigue, and multiple tender points that occur in precise, localized areas, particularly in the neck, spine, shoulders, and hips. Widespread pain must be present for at least three months (Wolfe et al., 1990).

Fibromyalgia has been studied since the 1800s, however, the term fibromyalgia was not introduced until 1976. Fibromyalgia was first recognized by the American Medical Association as a “true” illness and the cause of disability in 1987. It was not until 1990, when the American College of Rheumatology developed a diagnostic criteria for doing fibromyalgia research, that the term gained wide usage (Marson & Pasero, 2008).

Because no clear physiological explanation for fibromyalgia exists, the disorder is referred to as a syndrome rather than a disease (National Fibromyalgia Association, 2009). The median age of onset for FM is between the ages 29 and 37; however FM can develop from childhood to old age (Johnson, 2008). Fibromyalgia occurs most frequently in women; approximately nine out of ten patients with FM are women (Wolfe, Ross, Anderson, Russell, & Herbert, 1995; Yunus, 2001).

Key Concepts and Conceptual Framework

The primary symptoms of FM are widespread, diffuse pain, often including: heightened sensitivity of the skin, tingling of the skin (often needlelike), achiness in the muscle tissue, weakness in the limbs, nerve pain, and cognitive dysfunction. Digestive symptoms are also common in fibromyalgia and include: difficulty swallowing, heartburn, gas, cramping, abdominal pain, and alternating diarrhea and constipation. Other symptoms attributed to FM are: chronic paresthesia, physical fatigue, irritable bowel syndrome, genitourinary symptoms such as those associated with the chronic bladder condition interstitial cystitis, dermatological disorders, headaches, myoclonic twitches and symptomatic hypoglycemia. Although it is common in people with fibromyalgia to experience widespread pain, it may also be localized in areas such as the shoulders, neck, back, hips, or other parts of the body. Many sufferers also experience varying degrees of temporomandibular joint disorder (Fibromyalgia Resource Information, 2005).

Symptoms can have a slow onset, and many patients have mild symptoms beginning in childhood, such as growing pains (Johnson, 2008). Johnson indicates that adolescents may have symptoms of FM and attempts are underway to classify a disorder called juvenile primary fibromyalgia syndrome. According to White, Lemkau, and Clasen (2001) FM symptoms are often aggravated by unrelated illness or changes in the weather. Symptoms can become more or less tolerable throughout daily or yearly cycles; however, many people with fibromyalgia find that, at least some of the time, the condition prevents them from performing normal activities such as driving a car or walking up stairs (White, et al.). The following factors are said to temporarily increase

the suffering of patients: cold weather, changes in atmospheric pressure, malnutrition, physical activity, lack of deep sleep and increase in stress (White, et al.).

Diagnosis

FM is diagnosed based on a history of at least three consecutive months of widespread bilateral pain (Clauw & Crofford, 2003). The pain is in response to stimuli not typically considered painful, and a reduced threshold for reporting pain (Price & Staud, 2005). Chronic widespread pain must be present in at least three body quadrants, as well as the axial skeleton, and 11 to 18 tender points located in specific regions throughout the body. Tender point testing is done manually or with an algometer using deep pressure of 4 kg or less (Staud & Domingo, 2001).

Fibromyalgia Controversy

Since the discovery of FM, there has been much controversy regarding the disorder. As noted by Celiker, Borman, Oktem, Gokce-Kutsal, and Basgoze (1997) there is considerable debate in the literature concerning the role of psychological factors in fibromyalgia. Some argue that FM marks the onset of psychological factors such as depression and anxiety. Others state that FM is developed out of psychological abnormalities such as depression, anxiety, and various neuroses. Some studies have suggested a predisposing personality type for developing FM (Ahles, Yunus, Riley, Bradley, & Masi, 1984).

Biological issues have also been considered in the development of the disorder. Researchers indicate that FM sufferers do not enter into deep restorative sleep

(Moldofsky, 2008). Several infectious diseases, such as Lyme disease and Hepatitis C, have been implicated as predisposing factors for the development of FM (Albin, Neumann, & Buskila, 2008; Goldenberg, 1993; Ram & Shoenfield, 2008). Investigations (Buskila, Nuemann, Vaisberg, Alkalay, & Wolfe, 1997; Friedman & Weisberg, 2000) have focused on the role of physical trauma, such as an automobile accident, in the development of FM. Neuroendocrine abnormalities have also been shown to exist in patients with FM (Dessein, Shipton, Stanwix, & Joffe, 2000; Johnson, 2008; Weissbeckera, Floyda, Dederta, Salmona, & Sephtonb, 2006). Abnormalities in Growth Hormone secretion, which typically occurs in deep sleep, have also been indicated in FM given that patients with FM frequently have abnormal sleep (Bennett, 1998; Moldfosky, 2008). Researchers have also studied abnormal pain processing as a possible etiology for FM. According to Staud and Domingo (2001) “FMS patients have provided convincing evidence for central pain processing abnormalities that share features of neuropathic pain. These anomalies include: hyperalgesia, allodynia, abnormal temporal summation of second pain, neuroendocrine abnormalities, and abnormal activation of pain related brain regions” (p. 212).

Reich, Johnson, Zautra, and Davis (2006) stated, “there is still little widely accepted etiological or laboratory confirmation of specific physiological indicators” (p. 307). The treatment for FM is not standardized and the prognosis is unclear. Due to these issues, it is commonly regarded as difficult to treat and at times referred to as a “mystery disease” (Raymond & Bergland, 1994).

Because the medical community has not been able to confirm a definitive set of etiological factors in FM, some have suggested it may be a psychosomatic illness or

psychiatric disorder. In the past, FM patients have been diagnosed as hysterical given that most sufferers look well and have normal laboratory test results. Their chief symptom, pain, is quite subjective and is difficult to document (White, Lemkau, & Clasen, 2001). In addition, many FM symptoms also occur in depression and other psychiatric problems (Goldenberg, 1999).

Reich et al. (2006) examined the condition of “uncertainty of illness” as a variable involved in the adjustment of FM patients, relating it to psychological factors, affect and coping styles. They showed that illness uncertainty was significantly associated with anxiety, negative affect, and avoidant and passive coping. Their findings suggest that illness uncertainty acts as a risk factor for affective disturbances during stressful times. The researchers called for counseling interventions aimed at the level of illness uncertainty and encouraged researchers to study illness uncertainty as it is an important defining characteristic of FM.

Fibromyalgia, although a chronic illness, is not life-threatening. Yet, according to Wolfe et al. (1995) FM is a highly prevalent disorder associated with great suffering, and with very high rates of utilization of services. The symptoms of FM can disrupt performance, interpersonal relationships, and the pursuit of personal goals (White et al., 2001). Because there is no cure for FM, relief from symptoms is usually temporary. Conventional analgesics rarely reduce the pain, and even strong narcotics are often not sufficient to entirely eliminate the pain (Fibromyalgia, 2006). Chrisler (2001) stated that the unpredictability of chronic illness, the fact that these types of illnesses are incurable, the aggravating symptoms, and the general public’s unfamiliarity with these types of illnesses make living with one a frustrating and isolating experience.

Focus of the Study

Problem

Research to date does not identify a clear cause in the development of FM, which leaves others to speculate on the origins of the illness and some to even question the illness itself. Because there are so many uncertainties and unanswered questions about FM, counseling psychologists do not know how patients interpret the responses of others to their illness or how the unknown etiology affects patients. There are no current studies that examine how FM patients experience, perceive, and understand their illness in terms of having a syndrome with an unknown etiology. This lack of information limits a counseling psychologist's ability to provide effective therapy to patients with FM and to better understand how to help patients deal with the perceived responses of others concerning their illness.

Because illness uncertainty has been linked to anxiety and negative affect (Reich et al., 2006) it is important that counseling psychologists learn how a controversial illness is affecting their clients. Due to the high prevalence of FM and the common comorbidity with depression and other psychological conditions it is critical that counseling psychologists are familiar with the syndrome and are competent to provide help to FM sufferers. Interventions can then be created and aimed at treating negative issues that emerge out of illness uncertainty.

Purpose

There are several reasons why this study might impact counseling psychologists, medical health professionals, FM patients, and their friends and families. As previously mentioned, there is a gap in the literature in regard to the subjective experience of living with a controversial illness such as FM. The purpose of the present study is to explore the lived experience of FM patients and to describe these experiences. Specifically, this study will seek to identify commonalities of FM sufferers in terms of perceived responses of family, friends, co-workers, and the medical community to their illness. These commonalities will help educate counseling psychologists about what it is like for FM patients to live with a controversial illness and therefore increase their ability to provide better services to their clients with FM.

Friends, family members, and helping professionals may develop a deeper understanding of what it is like for someone to live with this controversial illness. This may lead to increased empathy in terms of their interactions with a FM patient. Patients with FM often report negative or unsatisfying interactions with medical practitioners, therefore; members of the medical community could use this information to be of greater assistance when treating FM patients.

Significance

The information gathered will inform counseling psychologists of what it is like to experience a controversial illness. This information will allow counseling psychologists to better help patients deal with the response or reactions to their illness experience by family, friends, medical practitioners and co-workers. This study will

expose more information about the daily suffering of FM patients in relation to their controversial illness and illuminate ways others, such as counseling psychologists, medical professionals, family members, and friends can be more responsive and helpful.

Definition of Terms

Chronic Pain: Pain that lasts longer than 3 months (Asher, 2005).

Illness Uncertainty: An illness with an unknown etiology and one in which the course of the disease progression is not predictable (Reich, Olmsted, & van Pumbroeck, 2006).

Medically Unexplained Illness: Physical symptoms for which no relevant organic pathology can be found after medical evaluation (Dirkzwager & Verhaak, 2007).

Parasthesia: An abnormal burning or prickling sensation which is generally felt in the hands, arms, legs, or feet but may occur in any part of the body (National Institute of Neurological Disorders and Stroke, 2009).

Polysomnography: An overnight test typically done at a sleep center and monitored by a trained technician. It records various physiological parameters, including an: EEG, EKG (heart rhythm tracing), respirations, oxygen levels, muscle tone, and eye and extremity movements (Peters, 2009).

Hyperaglesia: A greater-than-normal sensitivity to pain that may result from a painful stimulus or a lowered pain threshold (Mosby's Dental Dictionary, 2008).

Allodynia: A condition in which pain arises from a stimulus that would not normally be experienced as painful. (Mosby's Dictionary of Complementary and Alternative Medicine, 2005).

Organization of the Remainder of the Study

The relevant literature is reviewed in Chapter II, followed by a description of the methodology in Chapter III. Analyses of the data will be reported in Chapter IV, with discussion and recommendations for future research in Chapter V.

CHAPTER II

LITERATURE REVIEW

The overall intent of the literature review will be to assess research regarding the study of fibromyalgia and chronic pain. The lack of literature regarding the experiences of FM clients with a controversial illness and the lack of counselor understanding of these experiences will be shown to further support the need for the present study.

The literature review will provide an overview of the history of fibromyalgia and will specifically discuss research regarding the unknown etiology of fibromyalgia. Potential causes or influencers of the illness are described in an attempt to illuminate the uncertain nature of such an illness. Quality of life issues are reviewed to demonstrate the difficulties of living with fibromyalgia. Research studies focusing on the experiences of people with chronic pain in terms of achieving support from medical practitioners, family, co-workers, and friends are analyzed for similarities with FM patients. Finally, a review of illness uncertainty or studies focused on experiences with controversial illness is addressed.

History of Fibromyalgia

The European literature contains descriptions of musculoskeletal aches and pains dating back to the late 16th century when the term rheumatism was first used to describe muscular pain (Inanici, & Yunus, 2004). In the 18th century, according to Block (1993), medical practitioners began to identify painful but “nondeforming” soft tissue musculoskeletal disorders, which they titled muscular rheumatism. “Since the 19th

century, various forms of muscular rheumatism under different nomenclature have been described” (Inanici, & Yunus, 2004, p. 369). In 1904, Sir William Gowers introduced the term “fibrositis” which was used for the next 72 years (Inanici, & Yunus, 2004). During the late 19th and early 20th centuries, pain that resisted anesthesia and narcotic analgesics was considered to originate from psychiatric illness and fibromyalgia was one of these conditions (Williams, & Clauw, 2009). The term fibromyalgia was not used until the mid-1970’s. The change in name indicated the lack of evidence for any inflammation in connective tissues. “Thus, within the fibrous tissues there was –algia (ie, pain) but no –itis (ie, inflammation) (Williams, & Clauw, 2009). Inanici and Yunus (2004) make a case for Smythe (1972) as the grandfather of modern fibromyalgia. They argue he was the first to describe FM exclusively as a generalized pain syndrome, with poor sleep, fatigue, emotional distress, morning stiffness, and multiple tender points (Inanici, & Yunus, 2004). In 1981 Yunus et al. published the first controlled study of the clinical characteristics of fibromyalgia. In 1990, the American College of Rheumatology established its research criteria characterizing FM as a condition of both pain and tenderness (Wolfe et al., 1990). In 1991, Burckhardt et al. developed the Fibromyalgia Impact Questionnaire to assess physical and psychological functioning. In 1999, Bennett published a review article demonstrating evidence of central sensitization in fibromyalgia. “In the past 25 years or so, numerous controlled clinical and neuroendocrine studies have established FMS as a recognizable entity by its own right on a pathophysiologic basis” (Inanici, & Yunus, 2004, p. 376).

The Controversy

Medical practitioners are divided when it comes to the validity of fibromyalgia. Because there seems to be no understood pathology that explains FM symptoms, some medical practitioners suggest the pain experienced may be psychological. Other medical practitioners believe FM has a physiological origin that has yet to be determined. Because neither side has yet to definitively prove their case, a continuing controversy exists over whether FM is a real disease. An article appearing in the Sacramento Bee on May 31, 2009, (as cited in Clement Hall, 2009) noted, “Despite being recognized as a diagnosable disease by the American College of Rheumatology, the Food and Drug Administration and most insurers, fibromyalgia has not completely shed the stigma of being dismissed as “psychosomatic” by some in the medical establishment.”

Medical practitioners holding the belief that FM is psychological have offered several factors to explain the pain: (1) a medical practitioner may unintentionally induce a person’s pain by validating it; (2) A FM patient may be rewarded socially through disability compensation which reinforces the illness; (3) FM sufferers may be remarkably affected by social pressures that groom them to be sick; and (4) they have debilitated coping skills for handling stress (Patrick, 2008).

According to Goldenberg (1995) “critics of the concept of FM as a specific condition note the absence of any known physical or psychological pathology. . . . However, the absence of tissue pathology does not preclude the presence of recognizable illness, such as in migraine, irritable bowel syndrome, reflex sympathetic dystrophy, and most forms of regional pain disorders” (p. 3). Medical practitioners in support of FM as an identifiable illness, identify several unique physiological characteristics present in

those with FM that are absent in people without the condition: (1) FM patients have intrusion of alpha waves into delta sleep; (2) they have higher than normal levels of substance P (a pain promoting substance); and (3) a documented decreased blood flow in the thalami and decreased cortical blood flow, which play a role in pain perception, fatigue, and cognitive difficulties (Patrick, 2008).

The continued debate and controversy has a profoundly negative effect on those suffering with FM. Patrick (2008) sums up the costs of the debate to FM sufferers in the following way: more energy is focused on proving one's side of the debate than on exploring treatments; FM patients feel diminished when a medical practitioner treats their pain as psychological; and some medical practitioners refuse to treat FM patients which means many have not received adequate ongoing care.

The etiology section of the literature review will further explicate the controversy surrounding FM. There continues to be no definitive answers under each potential causal area investigated. This lack of definitive answers continues to fuel the controversy surrounding fibromyalgia, adding to the misery of an already difficult condition.

Etiology

The etiology of FM appears to be multifactorial in nature. Sleep abnormalities, neural sensitization, hormone imbalances, genetics, lower pain threshold, neuroendocrine and cerebrospinal alterations, and psychological factors have all been implicated in FM. Each of these factors are presented below.

Sleep Abnormalities

Sleep disturbance is a prevalent feature of FM. The American College of Rheumatology criteria for the classification of fibromyalgia identify sleep disturbance as a central associated symptom of FM (Lineberger, Means, & Edinger, 2007). Researchers report that 70-90% of patients with FM experience some form of sleep disruption (Rao, & Bennett, 2003).

Several researchers (Clauw & Crofford, 2003; Lineberger et al., 2007; Moldofsky, 2008) indicate that sleep disturbance is among the more common symptoms and report that the majority of FM patients present with sleep difficulties. Patients with FM report more difficulty falling and staying asleep, less hours of sleep, premature awakening, and taking more medications for sleep (Clauw & Crofford, 2003). According to Moldofsky (2008) patients with FM perceive their sleep to be un-refreshing and light regardless of how long they sleep. Many researchers report that a worsening of sleep increases subsequent pain complaints and distress, whereas increases in pain and psychosocial distress are commonly followed by increased sleep disturbance (Nicassio, Moxham, Schuman, & Geveritz, 2002; Roizenblatt, Moldofsky, Bendito-Silva, & Tufik, 2001).

Numerous studies have been conducted in which patients with FM were asked to self-report sleep disturbance and its effect on quality of life. A study by Theadom, Cropley, and Humphrey (2007) suggested that sleep quality in patients with FM was significantly predictive of pain, fatigue, and social functioning. These results support previous findings (Agargun et al., 1999; Nicassio et al., 2002) that poor sleep was associated with increased pain and fatigue in patients with FM.

Karlson, Luxton, Preacher, and Templin (2008) reviewed daily diaries of patients with FM to evaluate psychological functioning. The diaries recorded sleep duration, sleep quality, and records of positive and negative life events. The results indicated that sleep duration and quality were significantly related to affect and fatigue.

Osorio, Gallinaro, Lorenzi-Filho, and Lage (2006) utilized The Pittsburgh Sleep Quality Index (PSQI) to characterize and quantify the sleep complaints of patients with fibromyalgia. The PSQI is an instrument used to measure the quality and patterns of sleep in older adults. It differentiates "poor" from "good" sleep by measuring seven sleep domains: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction over the last month. In the study, the PSQI was applied to 30 patients with fibromyalgia and to 30 healthy control subjects. All PSQI component scores except sleep medications were significantly greater in fibromyalgia patients than controls. Sleep latency, sleep disturbances, and daytime dysfunction were the most frequent sleep difficulties reported by patients with FM.

Objective polysomnographic studies support subjective complaints by demonstrating increased arousals, the intrusion of waking-like alpha frequencies into non-rapid eye movement sleep, and excessive wake time to be common among FM patients (Linebarger et al., 2007). Several of these studies will be reviewed.

Roizenblatt et al. (2001) used polysomnography to look at alpha activity in non-rapid eye movement sleep of 40 female patients with FM and 43 healthy control subjects. In this study, blinded analyses of alpha activity in non-REM sleep were performed using time domain, frequency domain, and visual analysis techniques. Three distinct patterns of

alpha sleep activity were detected among the patients with fibromyalgia: phasic alpha (simultaneous with delta activity) in 50% of patients, tonic alpha (continuous throughout non-REM sleep) in 20% of patients, and low alpha activity in the remaining 30% of patients. All patients with fibromyalgia who displayed phasic alpha sleep activity reported worsening of pain after sleep. A post-sleep increase in the number of tender points occurred in 90% of patients with phasic alpha activity, 42% of patients with low alpha activity, and 25% of those with tonic alpha activity. Self-ratings of poor sleep were reported by all patients with phasic alpha activity, 58% of patients with low alpha activity, and 13% of those with tonic alpha activity. Patients with phasic alpha activity reported longer duration of pain than patients in other subgroups. Moreover, patients with phasic alpha sleep activity exhibited less total sleep time than those in other subgroups as well as lower sleep efficiency and less slow-wave sleep than patients with a tonic alpha sleep pattern. These researchers were able to document worsening of pain in patients with FM following poor sleep.

Carlson (2007) indicates that the brain produces alpha activity when a person is quietly resting but not asleep. Research investigating what causes the person with FM to wake up during their sleep cycle could provide much needed insight into treatment for patients with FM.

Alterations in non-rapid eye movement sleep pattern including an increase in alpha activity have also been replicated by Rizzi et al. (2004). These authors hypothesized that the sleep fragmentation seen in FM patients could be due to a cyclic alternating pattern. They compared 45 patients with FM and 38 healthy controls using polysomnography. They discovered that the cyclic alternating pattern rate was 29%

higher in the FM group as compared to the control group. They concluded that the microstructure of sleep may be what is affected in FM and that it is associated with pain. They believe that the pain of FM most likely reduces sleep efficiency and causes more light sleep, more cyclic alternating pattern, more arousals, and breathing irregularities. Moldofsky (2008) explains that “those with the phasic pattern of the alpha intrusion in slow wave sleep are more likely to have increased post sleep tenderness and subjective pain, poor sleep efficiency and less slow wave sleep than the other group” (p. 398).

Landis, Lentz, Rothermel, Buchwald, and Shaver (2004) compared 37 women with FM and 30 women without pain on sleep-spindle, a burst of brain activity visible on an electroencephalogram (EEG). The researchers used polysomnography to look at incidence, spindle wave time, and spindle frequency activity. The women with FM had a lower spindle-count and reduced spindle frequency compared with the control group. The researchers indicated that thalamocortical mechanisms of spindle generation might be impaired in patients with FM.

A different polysomnographic study (Roizenblatt et al., 2007) was used to document the effect active anodal transcranial direct current stimulation (tDCS) of the dorsolateral prefrontal cortex and primary motor cortex would have on the sleep structure in patients with FM. Thirty-two patients were randomized to receive either a placebo stimulation or active anodal tDCS. The results indicated that active anodal tDCS had a significant effect on sleep and pain specific to the site of stimulation. An increase in sleep efficiency was also associated with an improvement in fibromyalgia symptoms. This study demonstrated that brain stimulation improves sleep architecture in patients with fibromyalgia and this improvement was correlated with pain reduction. These results

support the idea that fibromyalgia may be associated with changes in brain activity that are responsible for sleep disturbances and pain.

Sleep disturbance is a prominent feature in patients with FM. Although there have been numerous studies focused on the different aspects of sleep in FM, a clear consensus has not been reached concerning the exact role or pathology associated with poor sleep in patients with FM. Patients with FM self-report difficulties with sleep and beliefs that these sleep problems increase their pain. Researchers are still unaware of whether sleep disturbances are part of a biological predisposition for FM or if FM in itself directly interferes with sleep (Moldofsky, 2008). There is however, substantial objective evidence that abnormalities in the sleep structure of FM patients does exist therefore giving credence to the subjective complaints.

Genetics

Some researchers hypothesize that genetics and familial factors may play a role in the etiology of FM. A genetic link among family members with FM was investigated by Yunus et al. (1999). They studied 40 multi-case families by looking at sibships. These authors concluded that evidence of a possible gene for FM was established. The researchers caution that their results were preliminary and call for further studies.

Arnold et al. (2004) assessed for family patterns of FM and for correlates of major mood disorder and FM within families. They compared patients with FM with patients with rheumatoid arthritis. Interviews and medical examinations were conducted with first degree relatives. The authors concluded that FM and reduced pressure pain thresholds aggregate in families and FM co-aggregates with major mood disorder in

families. This research demonstrates the possibility that genetic factors are involved in the etiology of FM and in pain sensitivity.

A genetic study by Bennett (2005) suggests the possibility of an increased prevalence of specific genotypes of neurotransmitters and their receptors in FM. Bennett concludes that polymorphisms of genes in the serotonergic and catecholaminergic systems are linked to the pathophysiology of FM.

There appears to be some genetic and familial factors that play a role in FM. According to Buskila and Neuman (2005) it is likely that several genes are working together to initiate FM. Again, evidence remains inconclusive and further genotype research is needed.

Psychiatric Disorders

A review by McBeth and Silman (2001) concluded that patients with FM have increased risk for many psychiatric disorders. This association has encouraged speculation about whether this provides clues to the pathogenesis of FM. Research regarding the role psychiatric disorders play in the development of FM will be reviewed below.

Depression

A strong association between depression and FM is cited in the literature (Artic & Toraman, 2002; Thieme, Turk, & Flor, 2004). Okifuji, Turk, and Sherman (2000) state that depression is the most common psychiatric disorder associated with FM. There have been several studies utilizing a variety of assessment measures concerning the prevalence

of depression in patients with FM. There appears to be a consensus that between 40-55% of patients with FM also experience depression. Ercolani et al. (1994) reported a 49% prevalence of depressive symptoms in patients with FM using the Center for Epidemiologic Study-Depression Survey. Kurkland, Coyle, Winkler, and Zable (2006) reported a 40% prevalence rate of depressive symptoms in patients with FM using the PRIME-MD questionnaire. Coster et al. (2008) reported a 54% prevalence of depressive symptoms in patients with FM using the Beck Depression Inventory.

In an attempt to explain the link between depression and FM, Johnson (2008) contends that it is most likely a bi-directional pathway; FM causes a reactive depression and FM may also be a symptom of depression. Some authors (Dunne & Dunne, 1995; McBeth & Silman, 2001) speculate that depression may be a reaction to the pain and disability of FM rather than the cause. Okifuji et al. (2000) indicate that depression is related to the cognitive appraisals patients with FM attribute to the effects of their symptoms on daily life. Gur, Cevik, Nas, Sarak, and Ozen (2006) argue that most patients with FM are not depressed. These authors believe that chronic pain may cause psychological symptoms such as anxiety and depression. They contend that the major difficulty in understanding the relationship between FM and depression is pain. The problem is that psychological abnormalities found in FM patients can be related to the degree of pain. Currently, the bodily processes through which depressive symptoms result in the symptoms of FM are unknown (McBeth & Silman, 2001).

Anxiety

FM has also been strongly associated with anxiety. Arnold, Crofford, Martin, Young, and Sharma (2007) reported a 71% prevalence rate of mild anxiety and a 45% prevalence rate of moderate to severe anxiety in patients with FM using the patient-reported Hospital Anxiety and Depression Scale. This study was conducted with a clinical sample and consistent with results from a different clinical sample study conducted by Malt, Berle, Olafsson, Lund, and Ursin (2000) which reported a prevalence of 27%-60% rate of anxiety disorder in patients with FM. In community populations the prevalence of anxiety in patients with FM decreases to approximately 35% (Raphael, Janal, Nayak, Schwartz, & Gallagher, 2006; White, Nielson, Harth, Ostbye, & Speechley, 2002).

Several studies conclude that anxiety is more likely to be a reaction to the pain and disability created by FM (Dunne & Dunne, 1995; Goldenberg, 1989). In a more recent study, Thieme et al. (2004) examined the relationship of psychosocial variables to depression and anxiety in patients with FM. They concluded that psychiatric disorders were not directly correlated with FM, but factors such as coping, past trauma, and spousal behaviors appear to mediate the correlation between psychiatric disorder and FM symptoms. Kurtze and Svebak (2001) explored the relationship of anxiety and depression with pain and fatigue in patients with FM. They concluded that fatigue was associated significantly only with depression and pain was associated with anxiety.

Confirmation of high rates of anxiety disorders in patients with FM warrants further study of the importance of these disorders in FM (Raphael et al., 2006). As to date, there is no clear meaning attributed to these associations.

Trauma

An association between FM and trauma has been hypothesized. Many researchers have implied a causative role of trauma for the development of FM (Bennett, 1993; Greenfield, Fitzcharles & Esdaile, 1992; Waylonis & Perkins, 1994). However, more recent research has shown evidence that trauma or injury in relation to FM has been insufficient in establishing any type of causal relationship (Buskila & Neumann, 2000; White, Carrette, Harth, & Teasell, 2000). There have been several more recent studies investigating the role injury or trauma may have in the onset of FM. These studies are reviewed below.

Tishler, Levy, Maslakoy, Bar-Chaim, and Amit-Vazina (2006) investigated whether whiplash injury was a possible trigger for the onset of FM in 153 patients with whiplash and 53 control patients with fractures. After more than 14 months of follow-up they concluded that whiplash injury and road accident trauma were not associated with an increased rate of FM.

McLean, Williams, and Clauw (2005) assessed whether a motor vehicle collision was a possible trigger to the development of FM. They concluded that a motor vehicle collision was capable of triggering FM, but not through direct injury. They reported that a motor vehicle collision could act as a possible stressor, when combined with other factors, which may trigger the onset of FM. A motor vehicle collision was described as one of the many stressors which could potentially trigger FM and the environment in which the stressor is experienced may determine whether there is an adverse result.

Although there is some evidence from earlier studies that FM is associated with physical trauma, the evidence is not definitive. Upon completion of a literature review from Medline from 1979 to 2000 (White et al., 2000) the authors agree there is no conclusive evidence supporting an association between trauma and FM. These researchers call for further studies to confirm this association and to identify whether physical trauma has a causative role in the development of FM.

Goldberg, Pachas, and Keith (1999) studied the relationship between traumatic events in childhood in 91 patients with chronic facial pain, myofascial pain, and fibromyalgia. Patients with FM reported the highest rates of childhood sexual and physical abuse. Walker et al. (1997) compared patients with FM to patients with rheumatoid arthritis. Patients with FM had significantly higher rates of victimization. The severity of the trauma experienced was significantly correlated with measures of physical disability, psychiatric distress, illness adjustment, personality, and quality of sleep in patients with FM but not in patients with rheumatoid arthritis.

In direct contrast, several studies have not found significantly higher rates of sexual abuse in patients with FM when compared to health controls (Alexander et al., 1998; Taylor, Trotter, & Cuska, 1995). Ciccone, Elliot, Chandler, Nayak, and Raphael (2005) attempted to resolve the inconsistent findings concerning the role of abuse. They conducted a community-based study in which they compared patients with FM and major depressive disorder, patients with FM without major depressive disorder, controls with only major depressive disorder, and controls without physical or psychiatric symptoms. These authors failed to find increased FM symptoms in the abused versus non-abused patients with FM.

According to Raphael (2006) traumatic events are commonly associated with conditions in which etiology is unknown. This author argues the same is true for FM. Raphael conducted a literature review regarding the role sexual and physical abuse play in the pathogenesis of FM. She concludes that evidence does not support a causal link between sexual and physical abuse and the development of FM.

Some studies have reported an association between post-traumatic stress disorder (PTSD) and FM (Cohen et al., 2002; Sherman, Turk, & Okifuji, 2000). Sherman et al. (2000) found PTSD symptoms in 56% of a sample of patients with FM, similar to Cohen et al. (2002) who found a rate of 57% when using a PTSD symptom scale. According to Resnick, Kilpatrick, Dansky, Saunders, and Best (1993) as cited in Raphael, Malvin, Janal, and Nayak (2004) these rates exceed the highest population rate for PTSD among women estimated at 4.6%. These authors conclude that some evidence does exist for the comorbidity between PTSD and FM but more evidence is needed. Raphael et al. (2004) indicate that PTSD may be a direct risk factor for FM or FM may be a direct risk factor for PTSD.

Although numerous studies have attempted to establish a causative link between the development of FM and some type of trauma, research to date does not indicate any clear connection. There appears to be conflicting research regarding the role sexual or physical abuse may have in the development or symptomology of FM. FM has been shown to have a high comorbidity rate with PTSD but the exact nature of this relationship remains unclear.

Cerebrospinal Abnormalities

Several studies have focused on cerebrospinal abnormalities that may play a role in the development or continuation of FM symptoms. Many researchers have utilized brain imaging techniques to gather evidence in support of such anomalies. These studies provide a wide range of results and are reviewed below.

Staud and Domingo (2001) reviewed the pathophysiology of fibromyalgia in the form of a literature review on Medline from 1965-2001. Based on this review, the authors indicated that FM is associated with reduced thalamic blood flow. Other functional central nervous system changes they found noted in patients with FM included increased signal intensity in the prefrontal cortex, insula, anterior cingulate, and cerebellum following noxious stimuli.

In a literature review concerning the pathophysiology and clinical features of FM, Simms (1996) looked at studies of regional cerebral blood flow (rCBF) using single-photon-emission computed technology (SPECT). Mountz et al. (1995) employed SPECT scans on 10 patients with FM and 7 healthy control subjects. SPECT revealed diminished resting regional cerebral blood flow in the bilateral thalami and caudate nuclei in FM patients compared to controls which correlated with pain threshold. Abnormalities of rCBF in the thalamus and the caudate nucleus are associated with low pain threshold levels. The caudate nucleus and thalamus are both involved in signaling the occurrence of noxious events (Mountz et al., 1995).

A study by Kwiatek et al. (2000) revealed reduced rCBF in the right thalamus and a trend toward reduced rCBF in the left thalamus. That study also showed reduced rCBF in the inferior dorsal pons and in a restricted region of the right lentiform nucleus.

Bradley et al. (1998) revealed that acute pain produces abnormal rCBF in the anterior cingulate cortex in patients with FM.

Gracely, Petzke, Wolfe, and Clauw (2002) used functional Magnetic Resonance Imaging (fMRI) to evaluate the pattern of cerebral activation during the application of painful pressure. Sixteen patients with FM and sixteen controls received pressure applied to the left thumb-nail bed. Each subject underwent fMRI while the painful pressure was applied. The functional activation patterns in FM patients were compared with the controls. Patients with FM showed significantly lower pressure pain thresholds. In the patients with FM, application of mild pressure produced subjective pain reports and cerebral responses that were similar to the effects produced by the application of at least twice the pressure in control subjects. Activations were seen in the contralateral primary and secondary sensory cortices suggesting an increase in painful input to structures involved in processing the sensory discriminative components of pain. Control subjects needed more pain in order to produce similar results, suggesting augmentation of pain sensitivity in patients with FM.

Several of the studies on brain imaging indicate reduced blood flow to the thalamus. According to Carlson (2004) the thalamus is believed to both process and relay sensory information to various parts of the cerebral cortex. Steriade and Llinas (1998) indicate that the thalamus plays an important role in regulating states of sleep and wakefulness. Sleep has already been shown to be disrupted in patients with FM and the reduced blood flow to the thalamus may play a role. Research exploring all the functions of the thalamus and how dysfunction could contribute to the symptoms of FM could be critical in determining treatments.

There appears to be one study that focused on the role of dopamine in FM. Wood et al. (2007) hypothesized that FM may involve a disturbance of dopaminergic neurotransmission. Dopamine has been implicated in several important functions including motor control and pleasure. Evidence is starting to indicate that dopamine may also be critical for pain modulation (Carlsón, 2004). During the Wood et al. (2007) study, eleven patients with FM and eleven control subjects were compared. A needle was inserted into the muscle of the right leg of participants. Subjects were informed that they would receive two intramuscular infusions of saline solution and that one might be painful and one might not and that the order of the infusions would be randomized. After receiving the infusions subjects rated the pain intensity. Subjects underwent positron emission tomography (PET) scans while receiving the infusions. Patients with FM reported experiencing the painful solution as more painful than healthy control subjects. PET scans showed that control subjects released dopamine in the basal ganglia during the painful stimulation, whereas patients with FM did not. For control subjects, the amount of dopamine released correlated with the amount of perceived pain. In patients with FM no such correlation was observed. According to Wood et al. (2007) the disrupted dopaminergic reactivity in patients with FM may be an important factor underlying the widespread pain and discomfort in FM. The researchers suggested that dopaminergic treatments be explored.

Kuchinad et al. (2007) investigated anatomical changes in the brain associated with FM. They studied the brains of 10 patients with FM and 10 healthy controls using magnetic resonance brain imaging (MRI). They discovered that patients with FM had significantly less total gray matter volume and showed a 3.3 times greater age-associated

decrease in gray matter than healthy controls. Gray matter loss was also found to increase with length of illness, with each year of FM being equivalent to 9.5 times the loss in normal aging. According to these researchers, FM appears to be associated with an acceleration of age-related changes in the substance of the brain. A similar study was conducted by Schmidt-Wilcke et al. (2007) in which they found evidence of decreased gray matter density in the thalamus of patients with FM.

Neuroendocrine Abnormalities

A wide range of neuroendocrine abnormalities have been suggested as possible contributors of pain and fatigue in patients with FM (Dessein, Shipton, Stanwix, & Joffe, 2000; Weissbeckera, Floyda, Dederta, Salmona, & Sephtonb, 2006). Each of these areas will be reviewed below.

Growth Hormone (GH) is required for muscle maintenance and repair (Carlson, 2004). Prominent GH secretion usually occurs during deep sleep stages (stages III and IV) which are frequently abnormal in patients with FM (Bennet, 1998; Moldofsky, 2008; Moldofsky et al., 1975). GH levels have been reported to be abnormally low in a significant amount of patients with FM (Bennett, Cook, Clark, Burckhardt, & Campbell, 1997). Bennett, Clark, and Walczyk (1998) looked at the use of GH replacement therapy in FM patients with low levels of GH. In this study 50 patients with FM were given either GH injections or a placebo for 9 months. There was a significant improvement in symptoms reported by the GH group following 6 months of therapy as compared to the placebo group. All patients who experienced improvement with GH injections suffered a

return of symptoms after discontinuing the GH treatment (Bennett, Clark, & Walczyk, 1998).

Substance P, a chemical in the body that increases awareness of pain, has been shown to be increased in the spinal fluid in people with fibromyalgia (Goldenberg, 2004). Four different cross-sectional studies by various groups in patients with FM noted an elevation of substance P in the cerebrospinal fluid of patients with FM (Bradley et al., 1996; Lie, Welin, Bragee, & Nyberg, 2000; Russell et al., 1994; Vaeroy, Helle, Forre, Kass, & Terenius, 1988).

Garrison and Breeding (2003) report significant similarities between the clinical findings in FM and symptoms of thyroid dysfunction and that a considerable amount of patients with FM have also been reported to have problems in the production or utilization of thyroid hormones. Garrison and Breeding (2003) found increased hyaluronic acid, a marker of deficiency of intracellular thyroid imbalance, in patients with FM leading to a conclusion that some patients with FM have thyroid resistance, type II hypothyroidism, which causes the symptoms of FM. Ribeiro and Proietti (2004) reported an association between thyroid autoimmunity and FM and depression. Pamuk and Cakir (2007) investigated the relationship between the symptoms of FM and thyroid autoantibodies. They determined a prevalence rate of 34.4% in thyroid autoimmunity in patients with FM, which was significantly higher in frequency when compared to a healthy control group at 18.8%. What remains troubling is that not all patients with FM have thyroid resistance.

Hypersensitivity

Schweinhardt, Sauro, and Bushnell (2008) report evidence that patients with FM have a hypersensitivity to unpleasant stimuli of other sensory systems. These authors observed altered olfactory perception in patients with FM as they rated unpleasant odors as more intense than control subjects. A study by McDermid, Rollman, and McCain (1996) discovered decreased noise tolerance in patients with FM. Patients with FM appear to have a generalized pain perception abnormality, with decreased tolerance to a variety of stimuli including pressure, cold, and heat (Berglune, Harju, & Kosek, 2002; Granges, & Littlejohn, 1993). Geisser et al. (2003) looked at the perception of contact thermal heat in 20 patients with FM and 20 healthy controls. Patients with FM showed significantly lower heat pain thresholds and tolerances as compared to the controls. This type of research demonstrates that the increased perception of unpleasant stimuli is not restricted to pain but could be a more general effect including altered perception of sensory stimuli.

Stress

FM is widely viewed as a stress disorder (Johnson, 2008). Several researchers have commented on psychosocial stress as a risk factor for musculoskeletal pain (Ariens et al., 2001; Bongers, Kremer, & ter Laak, 2002; Linton, 2000). Pain experienced by patients with FM has been shown to increase with mental stress (Van Houdenhove & Egle, 2004). The mechanisms by which stress is related to the pain in FM is however, poorly understood. A review by Johnson (2008) concludes that sympathetic nervous system axes and disturbances of the Hypothalamic-Pituitary-Adrenal (HPA) axis may

explain some of the symptoms associated with FM. The neuroendocrine abnormalities, discussed previously, are strongly influenced by the body's biological stress system (Carlson, 2004). This section will report on research concerning the disruption of the sympathetic nervous system axes and the HPA axis in patients with FM.

Many have reported abnormalities in sympathetic nervous system function for patients with FM (Cohen et al., 2001; Petzke & Clauw, 2000; Torpy et al., 2000). These researchers agree that it is not clear how sympathetic activation affects musculoskeletal pain during stress. Both a positive (Martinez-Lavin et al., 2002) and inverse (Okifuji & Turk, 2002) relationship between sympathetic activity and pain has been hypothesized in patients with FM.

Torpy et al. (2000) looked at whether corticotropin-releasing hormone (CRH) was pathogenic in patients with FM. They administered interleukin-6, a stimulator of the HPA axis through activation of hypothalamic CRH, to patients with FM and matched healthy controls. They discovered that adrenocorticotropin hormone (ACTH) release was delayed in patients with FM, which is consistent with a defect in hypothalamic corticotrophin-releasing hormones (CRH) neuronal function. Basal norepinephrine levels were higher in patients with FM, suggesting abnormal regulation of the sympathetic nervous system that may be caused by a chronically deficient level of hypothalamic CRH. These results show the mediating effects of CRH on the stress system at the hypothalamic and brain stem levels which could contribute to the symptoms of FM. The researchers suggest that these alterations of the stress system, along with central sensitization, may be factors in the amplification of pain perception and this hypoactivity is associated with underactivity of the stress system (Torpey et al., 2000).

Nilsen et al. (2007) examined the relationship among mental stress-induced autonomic activation and pain in patients with FM as compared to healthy controls and patients with chronic shoulder/neck pain. They had participants complete a stressful task for 60 minutes. They recorded continuous blood pressure, heart rate, finger skin blood flow, and respiration frequency before, during, and after the stressful task. They compared the physiological responses with the subjective reports of pain. They found abnormal cardiovascular responses in patients with FM. They also discovered a negative association between the heart rate response and the pain which developed during the stressful task in the group with FM. Patients with FM who had a small heart rate response experienced more pain during the stressful task and did not recover from the induced pain in the rest period. The patients with FM also had a larger finger skin blood flow response as compared to healthy controls. The authors hypothesized that these results, along with similar findings (Cohen et al., 2001, Kelemen et al., 1998) suggest a reduced stress-induced pain reduction for patients with FM (Nilsen et al., 2007).

According to Thompson, Lettich, and Takeshita (2003) stress seems to make the symptoms of fibromyalgia more severe and dysregulation of the Hypothalamic-pituitary-adrenal (HPA) axis may play a critical role. As Summarized by Thompson et al. (2003), serotonin and norepinephrine stimulate corticotrophin-releasing hormones (CRH) in the dorsal raphe nucleus and locus ceruleus. The CRH neurons, then stimulate the release of adrenocorticotropin hormone (ACTH), which leads to secretion of glucocorticoids at the level of the adrenal gland. Located between the hypothalamus and the level of the serotonin and norepinephrine production is a feedback loop. Appropriate feedback may

be prevented from deficits at neurotransmitter or hormonal levels which may have profound effects on the HPA axis (Thomson et al., 2003).

According to Thompson et al. (2003) cortisol and adrenocorticotropin hormone levels are commonly elevated in patients with FM. This type of elevation is characteristically associated with hyperarousal, however a study by Catley, Kaell, Kirschbaum, and Stone (2000) demonstrates this may not be the case in patients with FM. These researchers found elevated levels of cortisol in 21 patients with FM that could not be connected to any ongoing or acute stressor.

Another irregularity in the HPA axis involves a delayed but exaggerated ACTH response to CRH in patients with FM when compared to healthy controls (Torpy et al., 2000). These researchers suggest that stress may be pathogenic in patients with FM.

Although stress appears to play a role in FM, the precise nature of this relationship remains unclear. Further studies are needed to elucidate the role stress has in the development or continuation of FM.

Infections and Vaccinations

Infections, viruses, and vaccinations have been suggested as possible triggers of FM (Ram & Shoenfield, 2008). Based on a review by Albin, Neumann, and Buskila (2008) several infectious agents have been associated with the development of FM including: Hepatitis C, Hepatitis B, and Lyme Disease. Research is conflicted regarding the role, if any, infectious disease plays in the onset of FM. The literature regarding each of these proposed triggers is reviewed below.

Hepatitis C virus (HCV), has been associated with the development of FM (Albin, Shoenfeld, & Buskila, 2006; Buskila, Atzeni, & Puttini, 2008). Rivera et al. (1997) reported evidence for an association between FM and HCV infection in some but not all patients with FM. Goulding, O'Connell, and Murray (2001) provided evidence for a moderate increase in prevalence of FM in HCV patients. Kozanoglu (2003) revealed that FM was present in 18.9% of 95 patients with HCV as compared to only 5.3% of patients without FM. Other studies (Narvaez, Nolla, Valverde-Garcia, 2005; Palazzi et al., 2008) did not find an increased prevalence of HCV infection in patients with FM.

Dinerman and Steere (1992) suggested a possibility that chronic Lyme disease was an entity overlapping with FM. Patients with Lyme disease experience similar symptoms as patients with FM such as: prolonged fatigue, arthralgia, and difficulty with memory and concentration. They reported that Lyme disease may trigger FM but antibiotics do not appear to be effective in the treatment of FM. Hsu, Patella, and Sigal (1993) demonstrated that antibiotic treatment of patients with FM did not work and a positive test for Lyme disease was not warranted in patients with FM. Buskila, Atzeni, and Sarzi-Puttini (2008) indicate that FM may be triggered by Lyme disease but may also be frequently confused with that diagnosis.

Buskila et al. (2008) conclude that the possible role of vaccination in the development of FM still remains to be established. Allen (1988) suggested that rubella vaccine may have an etiological role in the development of chronic fatigue syndrome. Lathrop et al. (2002) screened all adverse events related to vaccination with Lyme vaccine in the United States between December 1998 and July 2000. Arthralgia, myalgia, and pain were the most common reactions. Buskila et al. agree there is some

evidence for the role of vaccination in the development of FM, but more studies are needed to confirm this association.

Adak et al. (2005) suggested that chronic hepatitis B carriage appears to increase the risk of FM. These researchers looked at fifty hepatitis B carriers and 50 hepatitis B negative controls. They discovered that FM symptoms were more prevalent in the hepatitis B group. They however called for more research to confirm this finding as this appears to be the first study of its kind.

Weather

Weather sensitivity is a minor criterion in the diagnosis of FM (Yunus, 1984). Patients with FM frequently disclose that the weather often influences their pain (Russel, 1989; White, Lemkau, & Clasen, 2001). Despite this information, very few studies have compared or related FM pain and weather. One study found that pain in patients with FM was affected positively by barometric pressure (Guedj, & Weinberger, 1990). Two other studies however; found no associations between barometric pressure and pain in FM patients (de Blecourt, de Voogd, & Van Rijswik, 1993; Hagglund, Deuser, Buckelew, Hewett, & Kay, 1994). A more recent study (Fors & Sexton, 2002) sought to evaluate the relationship between the daily weather and pain variations in patients with FM. They recruited 55 women and had them record pain ratings daily for two days. The ratings were then related to weather parameters. They concluded that a statistically significant relationship between FM pain and the weather was not found in their sample. This study however, was time limited and based on current weather conditions.

Cognitive Disruption

Numerous studies indicate cognitive difficulty as a prominent symptom in FM (Clauw & Crofford, 2003; Dick, Verrier, Harker, & Rashiq, 2008; Leurding, Weigand, Bogdahn, & Schmidt-Wilcke, 2008; Sephton et al., 2003). Neuropsychological deficits in patients with FM have been described in several studies mostly in working memory performance (Dick, Eccleston, & Crombez, 2002; Leavitt & Katz, 2006). Other researchers have failed to find significant decreases in cognitive performance when comparing patients with FM to healthy controls (Walitt, Roebuck-Spencer, Bleiberg, Foster, & Weinstein, 2008) or found that differences between groups disappeared after correcting for fatigue, pain, and depression (Suhr, 2003). A study by Glass, Park, Crofford, Fougine, and Clauw (2007) claims that working memory impairment in patients with FM is due to difficulties in managing competing/distracting information rather than an accelerated loss of information. The reason why FM patients experience cognitive deficits is still unclear (Luerding et al., 2008). Current research regarding cognitive deficits in patients with FM is summarized next.

Arnold et al. (2008) examined the perspectives of patients concerning the impact FM has had on their lives. Cognitive impairment, particularly in memory and thought processes, were commonly described among 48 women diagnosed with FM. Cognitive impairment was referred to as “fibro-fog” which has become a common term used in describing cognitive difficulties in patients with FM (Sumpton & Moulin, 2008). Participants reported a decline in mental acuity since the onset of FM reporting that they: forgot important tasks, were commonly unable to articulate their thoughts, had greater

difficulty with planning, and lost the ability to respond quickly when asked a question or when asked to perform a task.

Luerding et al. (2008) compared twenty patients with FM to twenty matched healthy controls. They measured verbal and non-verbal cognition using a short form of the revised Wechsler Adult Intelligence Scales with subtests assessing general knowledge, comprehension, similarities, block design, digit symbol test and picture completion. Verbal long-term memory was measured using the California Verbal Learning Test. Non-verbal long term memory was measured with the Rey Visual Design Learning Test. Verbal working-memory was measured with the digit span backward and non-verbal working memory with the Corsi block span. Voxel-based morphometry (VBM), a specific type of MRI, was used to evaluate for correlations between test results and brain structure. Results indicated significantly reduced working memory and impaired non-verbal long-term memory, limited to free recall condition, in comparison with the control group. VBM showed that performance on non-verbal working memory was positively correlated with grey matter values in the left dorsolateral prefrontal cortex, whereas performance on verbal working memory was positively correlated with grey matter values in the supplementary motor cortex. They also discovered that pain scores were negatively correlated with grey matter values in the medial frontal gyrus. They concluded that patients with FM suffer from neurocognitive deficits that correlate with local brain structure in the frontal lobe and anterior cingulated gyrus, which may be interpreted to indicate structural correlates of pain-cognition interaction. These researchers discuss the lack of clarity regarding the pathway of brain changes in patients with FM by noting that it remains unclear whether prolonged pain experience causes

brain changes or whether an altered brain structure predisposes one to pain amplification or chronification.

Dick, Verrier, Harker, and Rashed (2008) examined specific cognitive mechanisms involved in the cognitive disruption experienced by patients with FM. They compared 30 patients with FM to 30 matched controls in terms of attentional function and working memory capacity. They utilized neuropsychological tests to measure attentional functioning and working memory capacity. They discovered that performance of standardized everyday attentional tasks and working memory was impaired in the group with FM compared to the control group. Stimulus interference was also found to be significantly worse in the group with FM as the demands of the task increased. When the researchers accounted for pain levels, however they found no differences between groups on cognitive measures. They concluded that the pain in FM may play an important role in cognitive difficulty.

In a study that compared 10 patients with FM and 10 healthy controls, Kuchinad et al. (2007) found decreased grey matter volume in the cingulate, insular, and medial frontal cortices and in the left parahippocampal gyrus. In contrast, Schmidt-Wilcke et al. (2007) found a decrease in grey matter in the right superior temporal gyrus and the left posterior thalamus, and an increase in grey matter in the left cerebellum and in the striatum bilaterally.

Results regarding neuropsychological issues in patients with FM are heterogeneous. Some researchers agree that memory and attention deficits accompany FM but the exact nature of those difficulties remain unclear (Dick et al., 2002; Leavitt & Katz, 2006). Others have failed to detect such differences (Wallit et al., 2008). Some

researchers suggest that pain plays a role, (Dick et al., 2008) whereas others disagree based on findings that differences between groups disappear after correcting for pain, fatigue, and depression (Suhr, 2003). What is clear is that numerous studies indicate subjective complaints from patients with FM in terms of cognitive impairment (Anderson & Hovellius, 2005; Arnold et al., 2008; Reheim & Haland, 2006).

Treatment

There is no cure for FM and, therefore; symptom control appears to be the focus of treatment. There is no one specific intervention that appears to work for every patient, as each patient has different symptoms resulting in different responses to therapeutic interventions (Sumpton, & Moulin, 2008). Goldenberg et al. (2008) indicate that treatment most often involves medications in addition to self-management advice to pace activities and to follow a regular exercise program. Laswon (2008) describes FM as a complex and difficult to treat condition that requires a multidisciplinary approach that uses both pharmacological and non-pharmacological management. Current studies in regards to treatment options are reviewed.

Positive results in terms of symptom reduction have been reported with different types of relaxation training including: electromyography biofeedback, heart rate variability biofeedback, yoga, tai-chi, and meditation (Goldenberg et al., 2008; Hammond & Freeman, 2006; Hassett et al., 2007). Several authors have reported positive results with Cognitive Behavioral Therapy (CBT) (Nielson & Jensen, 2004; Thieme, Turk, & Flor, 2007) as seen in improvements in pain-related behavior, coping skills, and overall physical function in patients with FM. Others (Bennett & Nelson, 2006; Kendall,

Bertels, & Christensent, 2004) have found the efficacy of CBT to be inconsistent and when used alone, it did not offer any advantage over education or exercise programs.

Several researchers have focused on exercise as an effective form of symptom management. Modest effects on overall function and symptom reduction have been reported with aerobic exercise and water-based activities (Busch et al., 2008; Jones et al., 2006; Maquet et al., 2007). Improvements in overall well-being, sleep, psychological function, pain-pressure threshold, and both patient and physician-rated disease severity have been reported with these types of activities (Busch et al., 2008; Jones et al 2006; Maquet et al., 2007). Busch et al. caution that the ability to engage in long and strenuous physical activity is frequently limited by the pain associated with FM. Exercise that strengthens the skeletal muscles, such as stretching, is therefore considered to be of great importance for patients with FM (Busch et al., 2008).

Medications

Historically, antidepressants, particularly tricyclic antidepressants (TCAs) such as amitriptyline, trade name Elavil, and dothiepin, tradename Sinequan, have been the drugs of choice for pharmacological intervention in patients with FM (Arnold, 2006; Laswon, 2006). TCA's have been shown to be significantly effective in the management of sleep, pain, and fatigue in patients with FM (Baker & Barkhuizen, 2005; Goldenberg, 2007; Rao & Clauw, 2004). TCA's however; do not work for all patients with FM. According to Richeimer et al. (1997) the benefits seen with TCA's were limited to 25 to 45% of patients with FM. TCAs often come with adverse side effects and are not well tolerated (Arnold et al., 2004).

Research in regards to selective serotonin reuptake inhibitors (SSRIs) have shown mixed results (Anderberg, Marteinsdottir, & von Knorring, 2000; Arnold et al., 2002; Patkar et al., 2007). Among the SSRIs, fluoxetine, tradename Prozac, and paroxetine, tradename Paxil, were found to be more effective than citalopram, tradename Celexa (Arnold, 2006). A study by Arnold (2007) demonstrated that both amitriptyline and fluoxetine provided significant improvement in pain, function, and well-being when compared with placebo. These drugs still did not provide relief to all patients with FM.

Serotonin and norepinephrine reuptake inhibitors (SNRIs) have recently received attention in terms of their effect in treating symptoms of FM (Arnold, 2006). A study by Arnold et al. (2004) concluded that duloxetine, tradename Cymbalta, significantly improved measures of pain and several measures of quality of life in patients with FM. This study was conducted with only female subjects and a 50% decrease or greater in any pain score was only achieved in up to 41% of subjects. A similar study by Russell et al. (2008) demonstrated that duloxetine significantly improved symptoms of pain and quality of life when compared with placebo. A significant improvement was also shown in the area of mental fatigue but not in general or physical fatigue.

Milnacipran, tradename Savella, has been shown to relieve pain symptoms and improve measures of quality of life in patients with FM when compared with placebo (Gendreau et al., 2005; Vitton et al., 2004). These studies demonstrated a reduction of pain by 50% or greater in up to 37% of the patient population and a greater improvement in pain reduction was recorded in non-depressed subjects treated with milnacipran. According to Goldenberg et al. (2007) multidimensional symptom improvement in patients with FM was reported in 15-week, 6-month, and 12-month randomized

controlled trials with milnacipran. SNRIs are well tolerated and lack many of the adverse effects of TCAs (Arnold et al. 2004). As with other treatments, not all patients gained benefits from this type of treatment.

Holman and Myers (2005) conducted a randomized control trial in which they showed that the dopamine D3/D2 receptor agonist pramipexole reduced pain and improved fatigue and overall function in patients with FM. However, as seen with other pharmacological treatments, pramipexole failed to show a decrease in pain in all patients as only 42% of subjects reported significant improvements. In a 2004 study by Holman, ropinirole, another dopamine D3/D2 receptor agonist, failed to show a significant therapeutic response in patients with FM.

Anti-epileptic medications have also been studied in terms of their efficacy in treating FM. Arnold et al. (2007) showed that gabapentin, tradename Neurontin, improved pain, overall well-being, and sleep quality in patients with FM, however; a 30% or greater reduction in pain was only seen in 51% of patients. This medication also produced a high incidence of adverse side effects. Crofford et al. (2005) conducted a double-blind 8 week randomized clinical trial that compared the effects of pregabalin, tradename Lyrica, with a placebo on pain, sleep, fatigue, and health-related quality of life in 529 patients with FM, mostly women. Results showed that Pregabalin significantly reduced the average severity of pain, disturbed sleep, and fatigue as 28.9% of patients showed a 50% or greater improvement from baseline. Again, not all patients received benefit. This medication was shown to only have mild or moderate side-effects (Crofford et al.).

Various Benzodiazepines have also been studied in terms of efficacy in reducing the symptoms of FM. According to Arnold (2006) the most commonly used and studied, temazepam, alprazolam, and bromazepam have given inconsistent results in clinical trials in patients with FM. Hooten, Townsend, Sletten, Bruce, and Rome (2007) indicate that opioid analgesics, NSAIDs, and benzodiazepines either have no proven efficacy in the treatment of FM or provide little symptomatic relief.

Although a wide variety of treatment modalities have been studied in terms of efficacy in FM, an effective means of therapy is still lacking. Some treatments have demonstrated an improvement in overall health in only some patients with FM. Several of these studies have only been conducted in clinical trials and need confirmation in the everyday settings of patients with FM. Many of the pharmacological interventions focus specifically on the management of symptoms rather than on curing the illness. FM is a complex syndrome and in light of a clear etiology or known cure, requires a multidisciplinary approach in terms of symptom management.

Ethnic and Socioeconomic Differences

There has been little research to date investigating ethnic and socioeconomic differences in the experience of fibromyalgia. According to Schaefer (2005), “The experiences of African American women with FM have received little attention by researchers (p. 17).” This section will report on the few studies found conducting a literature search using Medline and Psycinfo databases. Gansky and Plesh (2007) assessed the distribution of widespread pain, tenderpoints, and fibromyalgia in African American and Caucasian women. They surveyed a community population of 1,334

women and classified for body pain spread. They found that an increase in body pain and tenderness was significantly associated with decreased subjective socioeconomic status. They reported that ethnic differences seem to exist as Caucasian women had significantly increased tenderness while African American women had more widespread pain. They stated that association of depressive symptoms and pain was stronger in African American women (Gansky & Plesh, 2007). Schaefer (2005) conducted a qualitative study focusing on the experience of FM in African American women. The results of this study highlighted one difference between African American and Caucasian women indicating that African American women were more likely to use their spiritual belief systems to help them with FM than Caucasian women.

Quality of Life

Claw and Crofford (2003) note that chronic pain most often leads to distress. They report that as a result of pain and the other symptoms associated with FM it is typical that patients start to function less well in their various roles. It is common for patients with FM to experience difficulty with spouses, children, and work, which increase symptoms and often lead to maladaptive illness behaviors. Typical behaviors include: isolation, a reduction in pleasurable activities, and decreases in activity and exercise (Clawu & Crofford, 2003). According to Van Den Kerkhof et al. (2003) chronic pain adversely affects quality of life and employment status and is associated with increased health care utilization. Anderson (1994) remarks that individuals with widespread pain seem to have higher pain intensity, have more somatic symptoms, experience more depression, and have the lowest scores for quality of life. Chronic pain

affects important basic relationships and both emotional and physical intimacy (Smith, 2003).

Arnold et al. (2008) conducted a qualitative study in which six focus group sessions with 48 patients with FM were conducted to assess the impact FM had on their lives. They discovered that FM had a profound impact on patients' lives. The results of their study were consistent with several other studies assessing the impact of FM on quality of life (Asbring, & Narvanen, 2002; Cunningham, & Jillings, 2006; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002). These researchers all agree that FM carries a serious emotional and physical impact that affects quality of life. This section highlights the common themes presented in each of the above-mentioned studies.

Most participants discussed feelings of shame and guilt resulting out of the necessity of rearranging priorities due to FM. Many participants found it difficult to plan events or to regularly attend already planned events because they could not predict how they would feel. The unpredictability of FM was cited as a difficulty in maintaining regular social activities. Most participants feared being judged by others as unreliable due to having to cancel and rearrange activities so often. They worried about skepticism and unsympathetic peers, co-workers, and family members. Guilt and shame were common emotional reactions to not being able to do things they once were able to do and to the lack of understanding experienced by others (Arnold et al., 2008; Asbring, & Narvanen, 2002; Cunningham, & Jillings, 2006; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002).

Another commonality was that FM affected participants' ability to establish and maintain physical and emotional contact with others. Many participants stated that the

most significant impact of FM on their marital lives was that the constant pain and fatigue of FM had greatly decreased their libido and desire for sexual intimacy. Another reduction in quality of life came from reduction in time spent with families and friends. Participants reported that their ability to complete the general tasks of daily living, such as chores, was severely limited by FM (Arnold et al., 2008; Asbring, & Narvanen, 2002; Cunningham, & Jillings, 2006; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002).

Participants described experiencing extreme sensitivity to light, sound, temperature, odors, and the weather. Most participants described experiencing unusual skin sensitivity as well. Participants commonly felt their immune systems were weakened as a result of FM, leading to an increased susceptibility to illness (Arnold et al., 2008; Asbring, & Narvanen, 2002; Cunningham, & Jillings, 2006; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002).

Frustration with the medical community and others was commonly expressed based on feeling unable to be understood. A common frustration was also experienced toward themselves based on their loss of previous functioning. Many felt burdened by attempting to keep their stress under control. They acknowledged the importance of keeping stress under control in that it helped prevent flare ups but was also difficult due to the social, mental, and physical impacts of living with FM, which simultaneously caused and increased their stress. Almost all felt FM was more difficult to manage when experiencing a great deal of stress, however they commonly experienced a lack of understanding from others when attempting to decrease stress (Arnold et al., 2008; Asbring, & Narvanen, 2002; Cunningham, & Jillings, 2006; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002).

Overall, the idea that quality of life greatly decreases for patients with FM appears to be consistent in both quantitative and qualitative studies. This seems to be one of the few aspects of the illness that research consistently supports.

Support from Others

According to Smith (2003) chronic pain is one of the most widespread and least understood problems in health care. Because the symptoms of FM are invisible, subjective, and nonspecific, physicians find it difficult to diagnose patients early on and tend to underreport or misdiagnose their illness (Golendberg, 1995). Most patients with FM will have seen several physicians and have had to undergo many medical tests before they receive a correct diagnosis (Schaefer, 2005). Individuals with FM tend to look well physically. Due to the absence of clinical markers of illness, physicians, along with family, friends, and co-workers, may refuse to believe that they have a medical illness (Soderberg & Lundman, 2001). Patients with FM typically feel a contradiction between their subjective certainty of their symptoms and the inability of medical science to prove their objective existence (Barker, 2002). Barker (2002) explains that patients with FM understand that those around them often do not recognize their symptoms as real. FM is sometimes identified as psychosomatic or a somatic presentation of mental illness by physicians due to the lack of clinical uniformity in diagnostic criteria, the failure of response to established medical treatments, and the fact that it cannot yet be traced to a known organic cause (Barker, 2002). Patients with FM find this extremely frustrating as not only are they forced to live with a debilitating illness but they are also burdened with proving its existence (Barker, 2002).

Cunningham and Mui (2006) interviewed patients with FM in order to gain a better understanding of what it is like to live with such a condition. Participants in their study reported that the diagnosis of FM lacked certainty and clarity, which added to their stress and frustration. Patients with FM reported that they continued to face skepticism and lack of support from health professionals during treatment due to the invisibility of their illness (Cunningham & Mui, 2006).

Werner et al. (2003) reported that the way physicians view the pain of women with chronic pain and handle their illness might be of critical importance for women's understanding of themselves and their ability to come to terms with a painful life. Women in chronic pain see the responsibility of health care providers as recognizing their suffering as well as their strengths (Werner et al.). Werner and Malterud (2003) asserted that it was hard work for women with chronic pain to make their symptoms socially visible, real, and physical when consulting with a physician. Asbring and Narvanen (2002) claimed that women with unexplained pain experience their illness as delegitimizing and stigmatizing because they experience their moral characters being called into question in interaction with others, and second, because they experience distress from being "psychologized" by their doctors. Frank (2000) asserts that illness demoralizes and that the ill person's need is for re-moralization. Upon describing the complexities of living with chronic illness, Werner et al. (2004) commented on our culture's marginalization of those suffering from medically unexplained illnesses.

Many physicians report experiences of personal failure, frustration, and feelings of being unable to help when dealing with patients with FM (Walker, Katon, Keegan, Gardner, & Sullivan, 1997). Malterud (1999) points out patients with FM report that their

experiences with doctors often make their health problems worse. Patients commonly feel they are experienced as difficult by physicians and their symptoms are sometimes referred to as somatization (Malterud, 1999).

Haugli, Stand, & Finset (2004) evaluated what patients with FM perceive as important in their medical encounters. They conducted focus group interviews with twelve patients diagnosed with FM. The main theme patients with FM considered important in the relationship with their physician was to be given a diagnosis that did not imply that the etiology of the pain was psychological. They reported that no objective criteria explaining their illness was a source of distress. They felt mistrusted by their physician when the physician failed to confirm a somatic diagnosis and experienced thoughts that the doctor was minimizing their symptoms.

Illness Uncertainty

Raymond and Bergland (1994) were the first to refer to FM as a “mystery disease.” The unknown etiology, multiple symptoms, significant suffering, and disability that fail to show consistent pathology characterize FM as a medically unexplained illness (Johnson, 2008). According to Reich et al. (2006) research implies that illness uncertainty may be a significant factor in understanding patients with FM in terms of their behavior and physical and mental functioning. They hypothesize that the lower levels of well-being and higher levels of psychological stress reported by patients with FM may be related to illness uncertainty. They point to the fact that patients with FM engage in more physician visits than other patients because, based on the uncertainty of their condition, they are highly motivated to reduce the uncertainty. Uncertainty also

appears to play a role in sensitizing patients with FM to the supportiveness of others (Reich et al., 2006).

The concept of illness uncertainty has been explored in other medical populations. Higher levels of anxiety were reported by women with breast cancer based on higher illness uncertainty (Wong & Bramwell, 1992). Mishel and Sorensen (1991) found that illness uncertainty was related to a reduced sense of personal mastery, lower optimism, and higher stress in patients with arthritis. Illness uncertainty was found to be the strongest predictor of psychological distress in a postpolio syndrome population (Mullins et al., 1995).

Johnson, Zautra, and Davis (2006) examined the role of illness uncertainty in pain coping in women with FM. They utilized questionnaires and interviewed 51 women with FM. Multilevel analyses showed that pain levels for those high in illness uncertainty predicted increases in coping difficulty. They concluded that illness uncertainty had a negative influence on coping efficacy.

Reich et al. (2006) found that illness uncertainty in patients with FM was significantly correlated with anxiety, depression, negative affect, and adjustment difficulties. Results of their study showed that patients with FM experienced a lower positive affect when they were experiencing stressful events, and this relationship was increased when illness uncertainty was higher. Their results support the idea that illness uncertainty is an important risk factor for patients with FM. Reich et al. (2006) call for further research exploring the condition of “mystery” in the quest to further understand and help patients with FM.

Reich, Olmsted, and van Puymbroeck (2006) examined how uncertainty of illness in patients with FM would affect their relationship satisfaction. They discovered that patients with FM reported a significantly higher level of illness uncertainty than patients with osteoarthritis. They also discovered that lower levels of partner supportiveness were related to dissatisfaction only when patients' uncertainty regarding their illness was high. These researchers also call for more studies examining the concept of illness uncertainty in patients with FM.

Living with Fibromyalgia

Little is known about what it is like to live with FM because very few studies have examined aspects of individual's experiences of FM (Cunningham & Jillings, 2006; Soderberg & Lundman, 2001). Cunningham & Jillings (2006) call for further qualitative research that may contribute to a greater understanding of what it is like to live with FM. Cunningham and Mui (2006) point out that living with FM requires experiencing and managing numerous symptoms whose invisibility and lack of predictability add to a host of issues affecting access to and experience of health care.

CHAPTER III

METHODOLOGY

This chapter describes the methodology employed in this study. A broad overview of the study is provided along with the rationale for utilizing a phenomenological approach. Research questions are described along with the processes used to collect, analyze, and validate the data. The nature of the participant sample is explained along with a description of the researcher.

Research regarding FM so far has been conducted primarily through the utilization of quantitative measures. The aim of this phenomenological study is to describe the meaning for several FM sufferers of their own lived experiences with a controversial illness. The focus is on what FM patients have in common as they experience the controversy and mystery in fibromyalgia. Using an exploratory qualitative approach, participants were asked to describe their experiences with a controversial illness. They participated in an open-ended interview process, during which a narrative of their experience was co-created by the participant and the researcher. The individual's narrative was then analyzed from a phenomenological perspective for the presence of common underlying themes unique to this sample.

Phenomenological Approach

Phenomenological research is one of the major methods of qualitative research. Phenomenology aims to understand the human experience concerning a particular phenomenon. This type of approach involves establishing relationships with the lived experience of the research participants through extensive study of a small number of

individuals (Moustakas, 1994). Phenomenology was used in this study as it allowed for the description of the meaning for several individuals of their lived experience with fibromyalgia. This type of design calls for the focus to be on describing what all participants have in common as they experience FM. In phenomenology, the researcher goes beyond past knowledge and experience to understand a phenomenon at a deeper level. Bracketing is a process of setting aside one's beliefs, feelings, and perceptions to be more open or faithful to the phenomenology. As a FM sufferer, this researcher acknowledged and bracketed her own experiences so as not to interfere with the study.

Research Questions

The aim of this study is to answer the following research questions: 1). How do FM patients experience and understand their illness; 2). How do the unclear origins of the syndrome impact patient perceptions and feelings regarding their illness; 3). How do FM patients describe the ways in which their close friends, co-workers, medical practitioners, and family respond and react to their condition; and 4). How do FM patients describe their experiences achieving support from these same people.

Role of the Researcher

In qualitative research, the researcher is a primary data collection instrument, therefore, it is critical of the researcher to make explicit any pre-conceived assumptions and to clarify one's role (Marshall & Rossman, 2006). In Appendix A, I share my personal story, focusing on how I became interested in this area. In the following section,

I attempt to make known the assumptions I hold in relation to this topic and that have informed my role as researcher in this study.

Assumptions Impacting My Role as Researcher

As a person who experiences fibromyalgia, I approached this study with certain ideas in mind related to the phenomenon under investigation. In my personal experience of fibromyalgia I find the unknown etiology of my illness troublesome. I also hold the belief that no one yet knows what causes fibromyalgia as none of the research has settled on a definitive cause. To me, there are only numerous theories and speculations, which I believe cause more distress to one experiencing an already troubling chronic illness. I have also had many negative experiences with members of the medical community in response to my illness. My best friend and husband are very understanding of my illness however, other family members and friends often do not understand, which has caused hurt feelings on both ends of these relationships.

I went into this study expecting to find similar results to my own experiences. I predicted unknown origin to be a highly troubling aspect of this illness and one that continued to agitate regardless of length of diagnosis. I assumed those with fibromyalgia would comment on the invisibility of symptoms and how this leads to miscommunication and distress. I forecasted mostly negative participant experiences with members of the medical community. I also expected conflict among extended family, friends, and co-workers, due to the invisibility of FM and its unpredictable nature, to be reported. I thought achieving support would be difficult and in-consistent.

In a true qualitative transcendental approach (Moustakas, 1994), in an attempt to perceive the data freshly and with as much objectiveness as possible, I have described my own experience with the phenomenon (see Appendix A for details) and bracketed out my views by answering the research questions as they pertained to me before eliciting the experience of others.

Participants

Twelve potential participants contacted this researcher to schedule an informational meeting to learn more about the study. Of those twelve, two participants were excluded from participation in the study as one did not meet the selection criteria for length of diagnosis and one had a pre-existing condition, Asperger's Disorder, which limited their ability to adequately respond to the research questions.

Of the ten participants who elected to take part in the study, there were nine females and one male with a mean age of 59.1, ranging from 43-86 years old. All ten participants identified as "white" and all were located in the Midwestern region of the United States. All participants had at least some college education. Four participants were married, one participant was single, three were divorced; with one in a current relationship, and two were widowed; with one in a current relationship. All participants were diagnosed with fibromyalgia by a medical doctor with a mean length of diagnosis of 8.85 years, ranging from 2.5-15 years. All ten participants were interviewed in-person either at their home or in this researcher's office in Southwest Michigan.

Data Sources

This study examines two primary sources of data: 1) a demographic questionnaire given to participants immediately following their consent to participate in the study and; 2) an audiotaped semi-structured interview with a mean length of 56 minutes, with the longest interview taking 75 minutes and the shortest at 41 minutes.

Consent and Approval

This study involved human subjects therefore, it was necessary to seek approval from the Western Michigan University Human Subjects Institutional Review Board. A favorable response was received on March 31, 2010 (see Appendix B for HSIRB approval letter).

Data Collection Methods

After obtaining informed consent (see Appendix C for informed consent document) semi-structured interviews were used in order to gather information regarding the lived experiences of patients with a controversial illness. Semi-structured interviews allowed participants to discuss at length the issues they viewed as important in experiencing their illness, while at the same time minimizing influence from the researcher upon the course of the conversation. The semi-structured interview questions were designed to shed light on the research questions. All interviews followed a semi-structured interview guide that was carried out in a conversation-like form by the researcher (see Appendix D for interview guide). A semi-structured approach was used to ensure specific content areas were addressed. Each interview was tape-recorded and

transcribed verbatim. Demographic information: gender, age, ethnicity, relationship status, length of current relationship, level of education, annual household income, and length of diagnosis, was obtained through a paper-and-pencil questionnaire immediately prior to the formal interview (see Appendix E for demographic questionnaire).

The seven stage model for phenomenological, qualitative interviews, presented by Kvale (1996) was used in the interview process. This model includes both logistical information, as well as ethical aspects of conducting qualitative interviews. A description of each stage is presented below.

1. **Thematizing.** This stage involves the formulations of purpose and scope prior to considering the research methods.
2. **Designing.** This stage involves engagements with all seven stages of the interview process with the intention focused on the knowledge and information to be gathered by conducting the research. It includes formalizing the design of the research by preparing the research proposal.
3. **Interviewing.** In this stage, interpersonal relationships are established with the research participants. A structured guide is used to interview participants. This stage also calls for reflection upon the gathered information.
4. **Transcribing.** This stage involves transforming the interview data from recorded conversation to written data to assist in the data analysis process. The data from this study was transcribed from the recorded interview into Microsoft Word files.
5. **Analyzing.** Taking into account the purpose of the study, the data was analyzed in written form and by using QSR NVIVO-8 computer software. Coding

transcript data and cross-case comparisons greatly enhance the capabilities of this software package. Major topics from the interview guide, along with emergent themes from the interviews themselves, were designated as codes in the form of both independent and hierarchical “nodes” within the software framework. Information from the demographic questionnaire was also considered when forming these hierarchical nodes. As part of this analysis, several techniques were used to accumulate and interpret data. Among these were data immersion, offering interpretations, and searching for alternative understandings (Marshall & Rossman, 2006).

6. Verifying. This stage involves judgments concerning the accuracy of the results of the analysis. Issues of generalizability, reliability, and validity of the analyzed data will be addressed in the course of the analysis and discussion of results.
7. Reporting. This final stage includes the writing and reporting of the findings in a manner that is consistent with scientific and ethical criteria in a way that is also easy to understand. Standard dissertation formatting will be used in the reporting of the results. Findings will be reported in a manner as to maintain the confidentiality of the participants.

Sampling, Subjects, Access, and Setting

Criterion sampling involves selecting cases that meet some predetermined criterion of importance (Patton, 2001). Ten participants with the diagnosis of fibromyalgia, who fulfill the ACR criteria for FM (Wolfe et al., 1990) were selected for

the study. Patients were selected for the study only if they have been diagnosed with FM for at least two years but not exceeding fifteen years. This criterion ensured participants had the diagnosis long enough to have experienced the phenomenon under study but not so long as to diminish the phenomenon.

Participants were recruited through a word of mouth process and posters inviting those with fibromyalgia to contact the researcher. Posters were placed on bulletin boards throughout various locations in South West Michigan (see Appendix F for poster). Those interested in learning more about the study were asked to contact this researcher by telephone or e-mail. This researcher mailed or e-mailed an invitation letter describing the study to the participants who indicated by phone or e-mail interest in the study (see Appendix G for invitation letter). After reading the invitation letter, potential participants still interested were asked to contact the researcher to schedule a meeting to learn more about the study and what participation would entail. Once potential participants contacted the researcher by phone, an initial meeting was set up either in the home of the participant or in this researcher's office, based on participant preference. The initial meeting was an appointment to go over the consent process. Prior to all interviews each participant was given a written consent form detailing the type of participation asked for in the study (see Appendix C for consent form). Interviews were only conducted with participants who agreed to the study and signed the consent form. Participants were notified that they could refuse to participate or quit at any time during the study without prejudice or penalty. All participants chose to participate for the full duration of the interview. Anonymity, voluntary participation, and informed written consent were all used in line with ethical practice.

Data Analysis Procedure

A phenomenological hermeneutic interpretation in the tradition of French philosopher Ricoeur (1976) was utilized to uncover the meaning of FM patients' experiences of living with a controversial illness. This method was chosen as it is both descriptive and interpretive. Using this method, the researcher attempts to explain and understand the meaning of experience by interpreting interviews. Hermeneutics involves cultivating the ability to understand things from someone else's point of view and to consider the social forces that may have influenced their outlook (Ricoeur, 1976).

Transcripts of the interviews were analyzed using the phenomenological hermeneutic interpretation process. This process consists of three stages. The first phase, interpretation, starts with a novice understanding that aims at obtaining a sense of the whole. During this phase the interview texts were read several times as open-mindedly as possible to gain a naïve understanding of the meaning of the FM participants' experience of living with a controversial illness (Ricoeur, 1976). This initial phase resulted in a written summary of the general findings. The first phase provided ideas for phase two, the structural analysis.

During phase two, this researcher examined the transcripts in terms of distinct entities to explain it. The interview text was divided into meaning units, each consisting of a sentence, a paragraph, or several paragraphs with similar meaning in relation to living with a fibromyalgia. The themes were then organized into subthemes.

The third phase is an interpretation of all the transcripts as a whole and was used to write a description of what the FM participants experience in terms of their controversial illness. The interview text was read as a whole, taking into account this

researcher's pre-understanding, the naïve understanding, and the results of the structural analysis. This researcher also wrote about her own experience as a patient with FM.

According to Ricoeur (1976), there is always more than one way to interpret a text. The interpretation must not only be probable but must also be one that is more probable than another interpretation. Thus, the interpretation was carried out from the perspective of the researcher's own experience living with fibromyalgia and her understanding of others living with fibromyalgia.

Self-Reflective Memos

Self-reflective documentation took on an important role in data analysis. According to Glaser (1995) qualitative memos describe the strategies of data analysis, identify links between categories and theoretical codes, and diagram the relationships between categories. Throughout the study, the researcher used self-reflective memos to record personal insights, questions or observations, and emerging theoretical propositions. Self-reflective memos were useful to the researcher as they aided in re-examination of selected data related to emerging categories and to gather more data to explain unanswered questions.

Confidentiality of Data

In the process of data analysis, each participant was identified by a pseudo name instead of their real identity. The names were created by the researcher who attempted to choose common names in current American society. All the information collected from the demographic questionnaires and the interviews was kept confidential, which meant

the participants' names did not appear on any papers in which the information was recorded or in the final write-up of this study. The researcher isolated the master list containing participant names and the corresponding pseudo names from all materials. The master list was destroyed after all data were collected.

The audiotapes, demographic questionnaires, and transcriptions were placed in a locked cabinet where they will remain for a minimum of three years. All transcriptions and coded data were stored in the researcher's computer file, but no information was stored with the participants' real names or other identifiable information.

Summary

This chapter presented the methodology employed in this study. A description of the phenomenological approach to research and its application to this particular study was provided. The research questions were described along with the role this researcher played in the study. The procedures of participant selection, data collection, and data analysis using phenomenological methods were discussed.

In summary, nine women and one man participated in the study and shared with the researcher their experiences living with fibromyalgia through an in-depth interview. The interviews explored their beliefs, thoughts, and feelings regarding what it is like to live with a controversial/uncertain illness.

The participants were selected based on their willingness to participate, diagnosis of fibromyalgia by a medical professional, and length of diagnosis of at least two years but not exceeding fifteen years. Participants were also selected based on their ability to understand and answer the interview questions.

Phenomenological theory methods of data collection and analysis were employed, such as in-depth interviews, verbatim transcriptions of interviews, self-reflective memos, various coding procedures, and identification of common themes. All the data collected and analyzed through phenomenological methods were organized into the research findings, which are presented in the next chapter.

CHAPTER IV

FINDINGS

Overview of Findings

This chapter provides answers to the research questions: 1) How do FM patients experience and understand their illness; 2) How do the unclear origins of the syndrome impact patient perceptions and feelings regarding their illness; 3) How do FM patients describe the ways in which their close friends, co-workers, medical practitioners, and family respond and react to their condition; and 4) How do FM patients describe their experiences achieving support from these same people. The first section of this chapter consists of a summary of the participant cases. The second section presents a phenomenological analysis of the data obtained from the participants. Finally, the chapter concludes with an overall description of the experience of FM.

The report of the findings includes not only the researcher's analysis of the data but also selected quotations from the participant interviews. The quotes from the participants serve as significant examples to help the reader better understand the participants' lived experience with FM. The quotes also reflect the participants' experiences in a personalized manner with the exact words shared by them, allowing their voices to be heard.

Case Summaries

The first section of this chapter presents a summary of all cases included in this study. To preserve confidentiality, all names have been changed by the researcher to

common names in contemporary American society. Names reflecting the true gender of the participants have been used.

Cumulative Summary of Participants

All ten participants were interviewed in-person either at their home or in this researcher's office in Southwest Michigan. Table 1 provides a summary of information gathered in the demographic questionnaire completed by each participant (please see Appendix E: Demographic Questionnaire).

In the current study there were 9 females and one male with a mean age of 59.1, ranging from 43-86 years old. All ten of the participants identified as "white" and all were located in the Midwestern region of the United States. All participants had at least some college education. Four participants were married, one participant was single, three were divorced; with one in a current relationship, and two were widowed; with one in a current relationship. All participants were diagnosed with fibromyalgia by a medical doctor with a mean length of diagnosis of 8.85 years, ranging from 2.5-15 years.

Table 1. Participant Demographics

Participant Name and #	Gender	Age	Ethnicity	Relationship Status	Length of Relationship	Level of Education	Income	Diagnosis by M.D.	Length of Diagnosis
Cindy #1	F	58	White	Widowed/Current Partner	6 Years	Some College	>\$20,000	Yes	6 Years
Kerri #2	F	62	White	Divorced/Current Partner	13 Years	Some College	\$43,800	Yes	15 Years
Amy #3	F	62	White	Married	39 Years	College Grad	Retired	Yes	15 Years
Tanya #4	F	43	White	Married	3 Years	Some College	\$130,000	Yes	7 Years
Sara #5	F	86	White	Widowed		Some College		Yes	2.5 Years
Holly #6	F	56	White	Married	37 Years	College Grad	\$40,000	Yes	9 Years
Mary #7	F	58	White	Single		College Grad	\$24,000	Yes	4 Years
Jill # 8	F	62	White	Divorced		Some College	\$20,000	Yes	15 Years
John # 9	M	58	White	Married	38 Years	Some College	\$100,000	Yes	12 Years
Beth #10	F	46	White	Divorced		Some College	\$9,600	Yes	3 Years

Summary of Individual Participants

Participant 1: Cindy

Cindy is a White female who is 58 years old. She was interviewed in her home. She was widowed approximately ten years ago but has been in a relationship for six years with a man she calls her lifetime partner. Cindy has completed some college education. She reportedly earns less than \$20,000 per year and receives disability income due to her illness. She was diagnosed by a medical doctor with fibromyalgia six years ago. Cindy worked as an in-home caregiver for approximately 15 years but had to quit due to the severity of her fibromyalgia symptoms. She reported “fibro fog,” memory difficulties, and exhaustion as the main reasons she had to quit working. Due to these issues, she worried she would make errors with patient medications. Cindy disclosed that the severity of her symptoms often prevent her from engaging in family and social functions. Her FM symptoms are typically worse in the morning and after remaining in one position for too long. She believes she has a supportive partner who understands her illness as best as anyone could who did not have FM themselves. She has found the most relief from natural approaches to symptom management such as weekly massage.

Cindy indicated that she did not know the cause of her illness. She initially questioned her diagnosis as she had what she described as a “bad experience” with the first doctor who diagnosed her. She was frustrated as she was not sure she was getting the correct diagnosis as this doctor disagreed with other diagnosis’ she received even though they had been verified by a pathologist and several medical doctors. She indicated this by stating:

I said you know this is fine and dandy but just to tell me I have fibromyalgia because you think this is what I wanna hear is not what I wanna hear. I wanna know that yes I really do have it or is it just something you just slap on any ole thing you wanted.

She switched physicians as she was un-happy with this one and she indicated that “he did confirm that yes I did have fibromyalgia and I had all the trigger points, all 18 of them.”

Participant 2: Kerri

Kerri is a 62 year old White female who was interviewed in an office setting. She has been previously divorced but currently in a relationship with her significant other for the past 13 years. Kerri has completed some college education. She reportedly earns an income of \$43,800 per year. She received a diagnosis of fibromyalgia fifteen years ago by a medical doctor. Kerri had always been an avid painter, selling many paintings to local businesses. She had to mostly give this up due to the severe pain she would feel both during and after this activity. Kerri reported that her symptoms are most severe in the morning or after repetitive types of activities. She indicated that her symptoms could be severe at times and better at others. She is never free from pain, but found that sometimes she could engage in normal everyday activities without an increase in pain or exhaustion.

Kerri also indicated that she did not know the cause of her illness. She explained: I absolutely have no idea, none. I think my doctors had said way back at the beginning that it might be caused by maybe not getting enough rest. When I was young I tended towards being a workaholic and I did not get more than like five

or six hours of sleep a night. I had a family and I was just on the go all the time and didn't get enough rest. Maybe that's it, maybe not, I don't know. It's all I can come up with.

Participant 3: Amy

Amy is a 62 year old White female. She was interviewed in an office setting. She has been married to her husband for 39 years. She is a college graduate. She was diagnosed with fibromyalgia by a medical doctor 15 years ago. Amy retired from her job at a college working in the Division of Students with Disabilities at the age of 58 as she could no longer work due to her fibromyalgia. Persistent exhaustion, slowness, overall body pain, and a lack of understanding from her employer were the main reasons leading to her decision to stop working. She reported the most relief from her symptoms through natural approaches such as soaking in Epsom salt baths and massage as well as managing her schedule. She believes she had a major turning point in illness acceptance and symptom management when she learned to say no to others without guilt and no longer tried to keep an immaculate home. She now acknowledges how her body feels on a daily basis and makes plans accordingly. She feels she has a much better handle on her symptoms and overall well being than when she was first diagnosed.

Amy stated that she did not know the cause of her illness either. She speculated that it may have been the result of several episodes of mono earlier in her life. She asked for several medical tests as she was not feeling well and stated "they told me there was no other lab work to run. Well we could do this but we think it's in your head. So I don't know if that's where it really started." She also had a thyroid problem that went un-

diagnosed for many years. She tried to get her doctor to run different tests for her thyroid. According to Amy, they only ran a test on her TSH, Thyroid-stimulating hormone, which always came back okay. She eventually had trouble breathing and they finally agreed to give her an ultrasound. Amy reported:

They discovered a two inch nodule on one side and a four inch nodule on the other side. Then they did an MRI, it was cutting off my airway. I had a total thyroidectomy . . . I woke up on the recovery room table and nothing hurt. So I think the thyroid in my case played a role in the overall condition and the TSH was still fine the day I went into surgery but I can tell you the difference in how I feel now since before the surgery and I think that was an issue that I couldn't get anybody to look at. They ran one test and the TSH was fine.

Participant 4: Tanya

Tanya is a 43 year old White female who was interviewed in an office setting. She has been married to her husband for three years. She has completed some college education. Tanya reported her household income as \$130,000 per year. She was diagnosed with fibromyalgia by a medical doctor seven years ago. Tanya has chosen not to work due to her symptoms. She experiences severe pain in her arms which prevents her from lifting and doing routine tasks. She finds this difficult as she reported she has a very active mind with a body unable to match it. At times, Tanya will engage in activities, such as sporting games, with the understanding that she will be in intense pain afterward.

Tanya also did not know the cause of her illness. She tried to come up with some type of answer and speculated:

I know the doctor says a lot of time a major trauma can cause it. I can't really think of a major trauma I might have had. I know that they did a lot of surgery thinking it was other things . . . I don't know, I can't think of any reason.

Participant 5: Sara

Sara is an 86 year old White female. She was interviewed in an office setting. She is widowed and lives alone. She is currently not in a romantic relationship. Sara has completed some college education. She was diagnosed with fibromyalgia 2 ½ years ago by a medical doctor. Sara often has trouble distinguishing her FM symptoms from normal symptoms related to old age. She believed she was handling her diagnosis well and did not believe FM interfered with her life too much. She remains active in various organizations but often feels a little more tired and achy than she used to.

When asked about the cause of her illness, Sara stated “the way I understand it, they don't know what causes it or where it comes from. I'm inclined to believe there is some connections between surgery and this. I can't recall having this before I had knee surgery.”

Participant 6: Holly

Holly is a 56 year old White female. She was interviewed in her home in Southwest Michigan. She has been married to her husband for 37 years. She has completed some college education. Holly has a reported yearly income of \$40,000. She

was diagnosed with fibromyalgia by a medical doctor 9 years ago. Holly had to stop working two years ago due to the severity of her medical problems. Holly experiences her worst symptoms in the morning. It is often very difficult for her to get out of bed and get moving. Holly was teary eyed throughout most of the interview and it appears she sees her illness as a major loss of her former self and previous life. She wishes she could still work and contribute to the household income.

When asked about the origin of her FM, Holly simple stated no, she did not know the cause of her illness. She did not provide any speculation as to the cause.

Participant 7: Mary

Mary is a 58 year old White female. She was interviewed in her home in Southwest Michigan. She is divorced and is currently single. She has completed some college education. Mary received a diagnosis of fibromyalgia from a medical doctor 4 years ago. Mary works part time at a day care where she reportedly earns an annual salary of \$24,000. Mary reported that her work duties have recently changed from supervising children during rest and nap times to much more active involvement. She stated that after work she is always exhausted and must take a nap when she returns home. She is concerned she may reach a point where she has to stop working. Mary reported that she already struggles to make it financially and believes she would not be able to live off of a disability income. She recently had her grandson move into her home to help her with household chores. She disclosed this has not gone well as he has become more of a burden than a help. Mary indicated that she suffers from depression but could not afford therapy.

When asked if she knew the cause of her illness, Mary said “I’ve heard stress and I did have a stressful period in my life.” Other than stress she could not think of any cause or triggering event.

Participant 8: Jill

Jill is a 62 year old White female. She was interviewed in her home in Southwest Michigan. She is divorced and is currently single. She has completed some college education. She was diagnosed with fibromyalgia 15 years ago by a medical doctor. She was employed as a bus driver for a small city but is currently on medical disability. Jill was frustrated that she could not use her illness as a reason to call in to work when her symptoms flared up. This led her to pursue disability which then caused financial difficulties. Jill reportedly earns \$20,000 per year. She explained that she received the most relief from FM symptoms through massage and yoga, both of which she can longer afford. Physical pain, exhaustion, and cognitive difficulties are her most common daily symptoms.

Jill expressed that no, she did not know the cause of her FM and believes:

There are too many opinions out there. I really feel that there’s a lot of theories even amongst the medical field and I think there’s professionals out there who claim to know fibromyalgia and it has a slant toward their own expertise. The one doctor is an expert towards migraines and seizures and so he wants to make my fibromyalgia slant in that direction. I don’t like those boxes because they are not addressing what I feel. They’re not addressing what’s happening to me . . .

maybe that's gonna be part of the answer but still as a patient, it's a frustrating road.

Participant 9: John

John is a 58 year old White male who was interviewed in an office setting. He has been married to his wife for 38 years. He has completed some college education. John works as a Machine Repairman and has been working with automated equipment for 40 years. He earns an annual salary of \$100,000 which he achieves by working a lot of over-time. He was diagnosed by a medical doctor with fibromyalgia 12 years ago. John mainly experiences persistent daily fatigue and an overall sense of aching muscles. He has not found anything that reduces his pain or fatigue.

John did not know the cause of his illness either. He speculated that it might be some kind of a virus. He also questioned his diagnosis:

I was questioning her because they're doctors that say there isn't such a thing and they've called it a variety of things, Epstein Barr Syndrome, heck, I don't know how many different names it's . . . you know I questioned her are we just saying it's fibromyalgia because we don't know what it is, you know is there something else that we ought to be looking for.

Participant 10: Beth

Beth is a 46 year old White female. She was interviewed in a small apartment in Southwest Michigan that she shares with a roommate. She is divorced and is currently not in a relationship. She has completed some college education. She was previously

employed at a VA Hospital where she sprayed organic compounds. She is medically retired from the results of chemical exposure and fibromyalgia. She reportedly earns a yearly salary of \$9,600, which has caused her to lose her home, personal business, and sense of accomplishment. Beth reports that her FM symptoms are severe on a daily basis. She received a diagnosis of fibromyalgia 3 years ago from a medical doctor.

Beth was the only one who was confident her fibromyalgia was a direct result of chemical exposure. She worked in a facility where she sprayed a “volatile organic compound.” She stated the company she worked for provided the wrong type of protection equipment for the chemicals they were spraying. She started getting eye infections, upper respiratory infections, ear infections, and sinus infections. It finally spread to her lungs causing heart valve regurgitation, pulmonary hypertension, and then attacked her bones. She indicated:

Before that I had no problems . . . I was perfectly healthy. I mean I worked full time. I had my own business, I had my own house, I had my own rentals, I had everything plus I’m a parent. You couldn’t keep me down. When that happened I just started going down-hill from there.

Beth also stated that the other women who were exposed to the same chemicals have all developed fibromyalgia. The company has since changed the way those specific chemicals are stored and handled.

With the exception of Beth, the participants did not know what caused their fibromyalgia. It appeared they had spent time considering possible causes but were unable to come up with anything definite. Many did not have positive diagnostic

experiences and some felt they were given the diagnosis because the medical community could not come up with a definitive answer as to what was wrong with them.

Next, I will report on the findings for each of the major research questions of the study. When reporting the findings, I will generally report more principal and widely occurring findings first under each category, with other less prevalent findings following in descending order. For the presentation of the findings, I categorized the numerical values of the number of participants responding into ranges that could be described with words. The ranges chosen are in Table 2 below.

Table 2. Participant Number and the Correlating Descriptive Word

Descriptive Word	Number of Participants Making the Response
Most	7-9
Many	5-6
Several	4-5
Few	3
Some	2-3

The Experience of Fibromyalgia

Research question 1: How do FM patients experience and understand their illness. Several themes emerged from analysis of the participants' responses in regards to what it is like to experience and understand fibromyalgia. Pain was one of the main descriptors of fibromyalgia. All participants talked about how their life had been altered due to fibromyalgia as they can no longer do things they used to be able to easily do.

Most elaborated on the idea that fibromyalgia sufferers do not look sick and therefore have difficulty getting understanding from others. Most thought others did not believe they were sick because on the outside they looked the same or healthy. Exhaustion and tiredness no matter how much sleep they got was another common factor. The depressing nature of the illness was commented on by most. The un-predictable and changing nature of the illness was described as not only part of the illness but a part that was frustrating. Frustration was one of the most commonly used terms by participants in their description of what fibromyalgia is like for them. Several participants talked about the frustration in not knowing if symptoms were fibromyalgia related or not. Many were also frustrated as they were unsure what symptoms were caused from their fibromyalgia or other factors. Cognitive difficulties were commonly reported either in answer to this question or when elaborating on other questions. Each of these descriptors and experiences will be described in more detail below.

Pain

All participants talked about experiencing pain when asked to describe what fibromyalgia is like. Cindy described her experience of fibromyalgia as “you’re in a lot of pain, discomfort.” Amy stated “I don’t like feeling like my body is going to break if I take another step.” Tanya described the location of her pain as, “my knees hurt a lot, my ankles hurt, but mostly it’s in my arms. The forearm muscles hurt 90% of the time.” Sara described her fibromyalgia as “very painful and frustrating.” She talked about how difficult it can be to simply move and she experiences a lot of her pain in her muscles. Holly experiences her worst pain in the morning and stated “some mornings it’s like I

don't want anything or anyone to touch me, just to move to get out of bed hurts." Jill described her fibromyalgia as "miserable because you hurt everywhere, you ache everywhere, I feel sometimes like every cell in my body hurts." When talking about his pain, John compared it to having little "bee bee's" of pain under his skin. He described his pain as aching muscles and tension. Beth gets a lot of pain all over, "not just muscles." Thus, the experience of pain was common to all participants. Some could identify certain parts of their body where the pain was more intense. Others described more of an all over experience of their pain.

Life Altering

Fibromyalgia, a lifelong illness, places restrictions on activities and causes one to make significant life alterations. A common theme for all participants focused on things they could no longer do or how fibromyalgia changed their life in major ways. Most participants had to give up things they enjoyed doing or they continue to do them with a lot of pain and discomfort. Several participants talked about how everyday simple things they used to take for granted are now very difficult and on bad days nearly impossible.

Amy captures this concept:

You just look like the everyday person and you get up, you go to work, you do what you need to do and you don't complain. There's a job to do, it's your job to do, but I don't think they understand that simple things become very, very complicated. Trying to mop a kitchen floor is torture, trying to clean a bathtub when you're down on your hands and knees is torture. Climbing on a ladder is almost impossible for me and reaching up over my head. On a bad day trying to

blow dry your hair with your arms over your head. Just simple things that everyone would take for granted.

Beth can no longer do a lot of repetitive things as “stooping bothers me, sitting too long, standing too long.” Tanya has always been an athlete and loves sports. She had to give up many of her athletic activities but continues to do some of them knowing she will experience a lot of pain afterwards. She expressed feeling as if “my life’s altered. Most of the things I could do, I can’t do anymore.” Kerri feels she is older than she is as she can no longer do the things she used to be able to do. Sara expressed that you can still do things but stated “it’s more difficult.” Holly admitted that even moving to simply get out of bed hurts. Mary is often so tired that she “cannot even read,” an activity she greatly enjoys. Mary also talked about a period where it took her “three days to do the laundry because the energy it took to get up and do it.” Beth finds fibromyalgia frustrating as it prohibits her from doing the things she used to do with ease. For Cindy everyday things have become painful:

It’s very painful to shave or to take a shower or to do a lot of things that are very easy tasks. It hurts to have somebody touch you sometimes. Now, I’m a huggy person and I don’t care how much it hurts, I’d rather have a hug. It’s the little things that people take for granted . . . You are also limited in what you can do. Like my oldest grandson, I used to play ball with him and as time progressed, I can’t do it. I used to play tennis, I can’t play tennis now. That bothers me. So you know, it’s those little things too that you don’t think about either.

Lack of Understanding and FM Sufferers Don't Look Sick

Fibromyalgia does not affect the physical appearance of its sufferers. Most participants highlighted this point as one of the main reasons others lack understanding regarding their illness. Amy emphasized this point:

It's a world I never thought I would live in. It's a condition that you don't look sick. It's kinda like convincing the public on the same tone, but it's totally different, that the neighborhood rapist is somebody who looks like a rapist. You don't look sick so there can't be anything wrong with you or you're making it up or you've got psychological problems or you want sympathy or no, I don't want that. I don't feel well. I don't like sleeping when I need to be doing something. I don't think a lot of people even understand it, even my spouse. Because I don't look sick, don't act sick, and you know if you're a cancer patient you got a bandana around your head . . . I don't know anyone who has this condition who looks like that. You just look like the everyday person.

Mary states her frustration as, "and because I don't look sick, people say but you look so good. Well, they don't wanna see it." Tanya described her fibromyalgia as "misunderstood . . . you do think you're crazy at first like you look fine and all of a sudden you think you're nuts." Sara described the support she gets from others as, "rough, because it doesn't affect the way you look. They're not too understanding because you don't look ill. They look at you and think you don't look sick to me." Beth's frustration lies with the lack of knowledge and awareness regarding her illness:

I think they need to have more meds, more research, more knowledge out there in the public. These doctors and employers look at you like you're a fruit loop cause there's not enough evidence out there. They say, oh, it's a mental illness, or it's caused from stress or this and that, bologna you know. There needs to be more, there's not enough.

All but one participant talked about wanting more understanding in response to their illness. John would like more understanding from his family and members of the medical community. He indicated this by saying, "I'd like them to seem to have some understanding...It would be nice if I thought my wife had more understanding of how I feel." Jill would like others to demonstrate more understanding of her illness and that it may at times prevent her from engaging in activities. Jill expressed this when she said:

If something is planned that I'm to be a part of and I'm having a bad day understanding would be great instead of but we had this planned, you said you would. (Understanding) instead of anger or I have really let them down, understanding about what the disease is and that there is a disease . . . that there is something there that really makes it a viable excuse to back out and to rest, that would be nice.

For Holly, understanding would mean, "to not have to explain myself to my family."

When speaking about her family Mary stated she wants "just for them to understand."

Cindy thought there was a lack of understanding from others due to the lack of physical markings from the illness. She stated that "when it's a disease or illness or however they wanna classify it as, that you cannot see, people don't understand." In response to fibromyalgia, Cindy would like understanding as evidenced when she stated "if someone

says that they do have this disease, I would like them to respond with I understand, I'm terribly sorry, you know and discuss it." Tanya indicated that she "just wants people to understand." She provided an example to illustrate her point:

If I ask for help not to look at me like I'm an idiot and come on what do you mean, you look healthy as can be. Or when they say, do you wanna hold my baby and you try to hold it and you can't and you have to give it back. I don't want them to think you don't like my kid or something like that so and I love children so that's been hard. I just want people to understand.

Sara would like "just understanding" in response to her fibromyalgia. She wants others to "just realize that your capabilities are less than what they were before you had that. Don't expect quite so much." Kerri would like others to "just understand that I'm just not comfortable all the time and just tolerate me being ten paces behind them all the time." Amy spoke about wanting the same understanding from others as she receives from her close friends. She described this as, "We'll make plans to go and those that really know me if I call you and say that I can't do it today they understand. I think they're disappointed, but you have to have that (understanding). It's hard to plan things long range."

A major part of the FM experience for several participants was the lack of recognition they felt their illness receives. These participants talked about their desire to have their illness recognized. Amy would like others to "just acknowledge" that she has an illness. For John, "it'd be nice if there was some acknowledgement that there was such a thing." Jill would like, "understanding about what the disease is and that there is a disease . . . that there is something there . . ." For Holly, "recognition would be really

good. Just recognition that it is a reality, that it's not in my head . . . just recognition that it is real." Cindy also described her desire to have others acknowledge her illness:

Like alcoholism, a lot of the time you can't tell that somebody's an alcoholic or you can't tell that somebody has cancer unless they're in chemo. So I guess it's like sometimes you have to have faith. You have to accept what isn't seen. Just like people, I'm a very religious person. A lot of people don't understand not being able to see God. You don't have to see God to have faith to know that he is there. So, therefore, you don't have to see that you have fibromyalgia to know that it is there. It's the idea that you don't have to see it to believe it or you don't have to see it to know that it's there, it's just what it is . . . You just have to know that what the person is telling you is true.

In response to her fibromyalgia, Holly would like "for the medical community to look at all the body of evidence that there is and at least to acknowledge it as a bone-fide disease and not a syndrome that's made up." John would also like some acknowledgement from medical professionals. When speaking about the medical community he stated, "it'd be nice if there was some acknowledgment that there was such a thing."

Feelings of Persistent Exhaustion and Tiredness

Most of the participants spoke about the persistent fatigue that most often accompanies fibromyalgia. For Amy, the constant tiredness she feels is frustrating. She expressed, "I don't like sleeping when I need to be doing something." Amy feels tired no matter how much sleep she gets. She stated, "To feel so tired . . . you slept 20 hours and

you just can't get one foot ahead of the other and you don't care you just don't care, just let me sleep." John admitted that his fibromyalgia symptoms started with feeling tired all the time. This is something he has never gotten over no matter how much sleep he gets. Beth feels exhausted and weak all the time. Mary goes through spells where she sleeps a lot more. She also indicated that "any interruption in my sleep makes a difference." For Cindy, "Fibromyalgia is one of the things that weakens, you don't think about that. Does it disrupt sleep? Absolutely!" Targeting sleep is often a course of treatment for fibromyalgia sufferers. Jill sums the frustration many feel by this:

I've never been given a medication that helps. I've been given medication to help me sleep because I was told that was my biggest problem. If I could just sleep at night I would just feel better and that's not right. I didn't feel better, I never feel better, I don't care how many hours I sleep. Some days I can just go through it, some days I get down-right cranky cause it has a lot to do with my sense of humor. Some days I just leave it here when I go to work.

Depression

Living with a chronic illness such as fibromyalgia can lead to feelings of depression. Most participants talked about how their illness has either contributed to depressive feelings or given them an understanding of how it could. When asked to describe what fibromyalgia is like for her, Tanya stated:

It's depression . . . it's hugely depressing . . . It's really the most depressing thing I've ever had. It can be nice out and you wanna be outside and you wanna be doing stuff and you think I can't do it or I just wanna do something.

Tanya also talked about being a Type A personality and the difficulty fibromyalgia has imposed on her personality style. She explained:

I'm constantly on the go so that takes a person like me totally out of my element and makes me have to sit and it's difficult. So, you tend to have a few more sad days . . . feeling like you're not really worth a whole lot if you can't do stuff, you can't take care of people.

For Cindy the limitations fibromyalgia imposes can understandably lead to feelings of depression:

It's bigger than what you think. It's not all just the typical pain, it's also the other symptoms. I'm not a highly depressed person, however; I can see if somebody has a tendency to be depressed how they could become more depressed, especially when your brain isn't functioning how you want it. You are also limited in what you can now do.

Holly talked openly about her own depression:

Sometimes it's difficult when I think that there's no cure. This is it, maintaining is the best you can hope for. I really did go through a period of time of depression. Until I was able to accept it, coming to terms with it, to make peace with it . . . As long as I was thinking about, I can't do this for the rest of my life, it became huge and unmanageable but when I started to learn, this is the day I have right now, this is the day I'm gonna live, tomorrow is tomorrow, it's not here yet. I need to let that go then it became more manageable.

Beth relates her depression to what fibromyalgia has taken away from her:

It weighs a heavy almost like a big depression on me because for me as active as I used to be, it's gone...I've lost everything I've worked hard for to leave my kids. It's gone because of this disease I got. So you take somebody that used to work and who you could never keep down and all a sudden they're sittin around getting fat, it's depressing!

For Amy, life get's depressing when she cannot do something she has always done. She explains:

So, I think people with fibromyalgia, I don't wanna generalize, I think you need something in an anti-depressant range because it does get depressing if you've lived a normal life and done what you've wanted and now you're young and you can't get out of bed and you don't wanna get out of bed. You've planned to do something and you just think, I can't do it or you've had a busy day planned and after the first thing you just say I can't do this anymore. That gets depressing. I think you can get mired in depression and I don't know that they offer or a lot of people want to admit that I have something that has altered, to me it's brain chemistry. There's something different in your brain chemistry. And I think there's a stigma against mental illness. Once you admit that you have mental things it's like your some deralect standing on the corner. You know I really think there is still a stigma about mental illness as much as there is about fibromyalgia.

Mary disclosed that she sees a psychiatrist "because there's a lot of depression with it."

John did not use the word depression but his description of fibromyalgia was similar in that he talked about the sadness in having this condition forever. He explained, "I hate to

think I'm gonna be this tired out and just not feel like doing anything for the rest of my life...I got a lot of stuff I'd like to get done but I just don't feel like doin it."

For many participants fibromyalgia was either depressing or understood as an illness that could lead to depression. For most, it was the pain along with the inability to do the things one used to do that led to depressive symptoms. For others, focusing on the lifelong aspect of the illness with no cure was when it became depressing.

Unpredictability

A troublesome aspect of fibromyalgia is the unpredictability and/or ever changing symptoms. For many participants, not knowing what each day will bring makes life difficult. Planning activities can be hard when you do not know how one's body will feel from day to day. Cindy expressed this by stating, "you never know what the days are gonna be like, some days are wonderful and some aren't so great." Amy found daily changes in her body. Clothing that fit her in the morning no longer fit by evening or was so uncomfortable she had to change. Mary found fibromyalgia to be unpredictable overall. She would have good periods which could instantly turn into bad periods. Jill found constant changes in her experience of fibromyalgia. She stated that her illness "ebbs and flows." John realized that his fibromyalgia has changed over the years. He was even told by medical practitioners "you may get better, you may stay the same, or you may get worse." Overall, having an illness with little predictability was viewed as a frustrating aspect by many participants.

Frustration

Many participants used some form of the word frustration when describing what fibromyalgia is like for them. These same participants often used the word repeatedly as they felt it truly captured the essence of fibromyalgia. The un-predictable nature, the lack of understanding from others, the lack of information about fibromyalgia, and the lack of what many feel is an inadequate response from medical practitioners were all linked to the frustration experienced. Kerri described her fibromyalgia as “really frustrating.” Amy talked about how her frustration builds up throughout her day due to things she cannot do, her pain, and how her body is uncomfortable. Both Sara and Holly repeatedly used the word frustration as an overall descriptor of their fibromyalgia. Jill related her frustration to the medical community and their inability to figure out what is wrong and how to ease her pain. She stated, “I knew something was wrong. So I just kinda felt like why can’t they find out what this is? I know I hurt and I hurt everywhere. It was just frustrating.” Jill expressed frustration from her persistent tiredness, weakness, pain, and her inability to do the things she used to do. Thus, the experience of frustration concerning many aspects of fibromyalgia was quite common.

Is it Fibromyalgia?

Another frustrating aspect of fibromyalgia elaborated on by many participants was the inability to tell if a symptom was related to their fibromyalgia or something else. According to Cindy, “sometimes I’m not sure if it’s the fibromyalgia or something else.” At times Jill questions if her symptoms are fibromyalgia or not. Beth talked about

cognitive difficulties and stated “my memory is shot and I don’t know if it’s caused from the fibromyalgia or caused from the chemical exposure.” Mary expressed sensitivity to temperature and stated, “I don’t know if this has anything to do with it . . . if I get cold it takes a long time to warm up and if I get warmed up it takes a long time to get cooled off. So, I don’t know if that has a lot to do with it or not.” Kerri questions a lot of her symptoms:

Now I have trouble getting around in the morning as quickly and I don’t know if that’s fibromyalgia related or not. I just don’t jump up and get at em anymore and I don’t know if that’s just being retired or if it has to do with fibromyalgia. I just don’t know. I find that I question a lot of things in my mind as to whether different things are related to that. I don’t necessarily get an answer but I know I think about it a lot . . . that’s the thing about fibromyalgia I think is that you don’t even know other than the chronic aches and pains. You don’t know how other things relate, whether they’re related to it or it’s totally un-related. I just don’t know.

Cognitive Difficulties

Several participants overtly talked about cognitive difficulties or experienced such difficulties during the interview process. Cindy compared her cognitive struggles to feeling as if she had “Alzheimer’s Disease.” She described this as her thought patterns “aren’t quite full.” Kerri had trouble remembering the questions and compared that to feeling a lot older than she is. Holly stated, “I miss having my brain here.” She called her cognitive difficulties “brain fog” which she described as not being able to think

clearly. She was frustrated with this as she was proud of the fact that she used to juggle a lot of information at the same time and manage it quite well. She can no longer do this.

Beth spoke about a specific incident to exemplify her cognitive difficulties:

My memory is shot . . . I don't know how to explain it so I'll give you an example. My son said did you ever find that gray cat that we had over on Linden Street. I said I remember the gray cat and he said Linden Street and I got to thinkin and thinkin and I said you mean in Jackson? He looked at me really funny and he just dropped it. It took my three days to remember Linden Street is only a block down the road . . . So I can't remember, it's my brain. But it's on and off, it's not consistent, it's irritating.

For Amy, her cognitive difficulties are a frustrating aspect of her illness. She described it as:

On the days you feel like your brain is gone, I can't remember anything. You transpose numbers in the checkbook, you put stuff in the refrigerator that doesn't belong in there, you don't know where you put stuff, this was not your life. It's like there's an alien living inside your body and you have to come to terms with it. I had to make friends with this alien or it's going to destroy me because I won't know where I put anything or did anything. Did I do it, didn't I do it? Now I've kept a day planner and I still keep a calendar at home. If I don't write it down anymore I don't know. I always knew what meetings I had to attend, what time I had to be there, when reports were due. I'm like, where am I supposed to be today?

Effects of the Unknown Cause

Research question 2: How do the unclear origins of the syndrome impact patient perceptions and feelings regarding the illness?

There were varied responses to this question. A few participants were not bothered by the un-known origin but were more focused on coping. A few were still frustrated and wanted answers. Some participants had done their own research in an attempt to discover a cause. One participant was initially frustrated with the unknown cause but has moved past her frustration. Almost all participants described pre-illness personality traits consistent with the summary of Type-A personality traits described by Karren, Hafen, Smith, and Frandsen (2001).

Not Bothered by the Unknown Origin

A few participants indicated they were not bothered by the unknown origin of their illness. These participants were more focused on coping with their symptoms.

Tanya sums this up:

I guess it doesn't really affect me. I don't really care where I got it. I just care that I have it and that I'd like to get rid of it . . . It's more of what do I do to maintain it, get rid of it. I know I won't get rid of it but control it.

Amy states, "You can't know everything, that's not the issue for me . . . So, I think just helping people cope with what it is and learning good coping skills and making the best."

Cindy was also more focused on coping than on the cause of her illness:

Knowing that there's really not a test they can take even blood, x-ray, anything else, it's more by your trigger points. I really had to figure out what I was gonna

do and how I was going to face this so that you know if I have a flare up, what can I do. I find, I myself, do more of the natural approach . . . I don't really feel one way or another because of its unknown, I just figured you know in life there are so many diseases out there that you don't know about, or that we don't understand about so this is just one of them.

Still Struggling and Wanting Answers

A few participants wish they had some answers to the cause of their illness. Jill summarizes her struggle:

In my mind I keep asking questions and asking them (doctors) questions and I still get blank looks. You know because we wanna know too, and people are questioning people. Well, they really don't want you to know they don't know so you get ignored a lot.

Sara wished for an answer to the cause of her illness and hoped the medical community would come up with a better way to diagnose people. John also wished for a better diagnostic system:

It'd be nice if there was a test they could give you that said alright you have fibromyalgia. Because all I've ever heard is you've got a list of symptoms they look for and if you have all these symptoms and you don't have anything else that's what you got . . . I'm a machine repairman . . . so I'm used to things are either this or that and you figure out they got a cause . . . I'd like to have a definite answer, this is what you got, this is how we know this is what you got..

Research

Both Mary and Holly looked at the research concerning fibromyalgia in an attempt to find their own answers to the cause and symptomology. Holly indicated:

I did a lot of research on my own trying to, I just thought well maybe I can figure something out. I guess that's human nature you know to wanna have some kind of control over what's happening, try to find a way.

Initially Frustrated

When asked how the unknown cause of her illness affects her, Holly admitted, "Well you know for a while it was very difficult, I struggled with that." As mentioned above, she conducted her own research in an attempt to find answers. Now she focuses on her spiritual beliefs as a means of coping. She claimed that "ultimately its (fibromyalgia) come to me from the hand of a good and sovereign God, I believe that. I don't waste my time on that (the unknown cause) anymore."

FM is an illness without a scientifically agreed upon etiology. A few participants were not concerned with the origination of their illness and instead focused their energy on coping. For several, the unknown cause was troubling and some had even done their own research in an attempt to identify the cause.

Response of Family, Friends, Medical Practitioners, and Co-Workers to FM

Research question 3: How do FM patients describe the ways in which their close friends, co-workers, medical practitioners, and family respond and react to their

condition? The overall themes in response to this question will be separated and reported in three categories: Family and friends, Medical Practitioners, and Co-workers.

Family and Friends

Several categories emerged that addressed the perceived response of family and friends. Among the most prominent responses were that friends were supportive and family members were not. Other responses included the idea of a mixed response. Some believed the response to their illness depended on who they were considering. Others believed they were supported whereas only one stated they perceived no support at all.

Friends Supportive and Family Not Supportive

The idea that friends were supportive of one's illness whereas family was not was reported by a few of the participants. For Holly, the response to her illness varies. She stated:

I think most of my family ignores it. They still want me to be juggling all the balls . . . I think it's all of our nature as human beings . . . we tend to view life from our own perspective of what's happening in me and so we look at all of life around us that way . . . My husband is a very busy man. He just forgets, he forgets because it's not his reality and that gets old having to explain it over and over and over again. . . I have some very good friends who are very, very supportive . . . If they don't understand they will ask questions . . . I'm very fortunate in that.

Mary also finds more support from her friends than family. She reported, “I really don’t have friends that don’t understand . . . family is kinda hard because sometimes I have to say I can’t do something that I would really like to do and be part of.” Amy found the response to her illness to vary as well:

Your real friends will stand behind you. It does irritate me when I’m having a bad day and my spouse will say what’s wrong with you now. I mean good god I’ve had it for 15 years . . . I don’t know whether he is just not thinking . . . that sometimes ticks me off.

Mixed Response

A mixed response was perceived by a few of the participants. Cindy viewed her boyfriend as supportive but not other members of her family. She found the questioning of her illness by others and the push to try whatever is suggested as non-supportive. She summed this by stating:

My boyfriend has been very, very supportive, he totally understands. He can see, like he sees me get up from the chair or he sees me move or he sees me not move. I have a sister who is in denial . . . for the most part sometimes some of my family members don’t wanna talk about it. They just wanna say, well we don’t wanna discuss it . . . I think at first when I was diagnosed with it, it was like, well how do you know, are you sure? Well no, I’m really not sure. This is what I’m told . . . A lot of people say, well have you tried this, have you tried that, you know should you be on this medication, well maybe you should go see this doctor, or how do

you know that's right. And, how do you know? So, I guess there's a lot of self and me people and sometimes you just say okay.

The response felt by Tanya is also mixed. She views her husband as supportive but finds that her daughter and others still do not understand. Tanya admitted:

At first, they didn't get it at all . . . They didn't get it . . . When I was diagnosed by a Rheumatologist, that's when they started. It's 2010 and people are finally realizing hey you shouldn't do this it hurts your arms. My husband won't let me do anything . . . he's super understanding. My daughter's eleven, she doesn't get it.

John believes that his wife and possibly his daughter do not understand or support him with his illness. He does believe his parents believe and support him. He, like most others, does not feel that people truly understand what his illness is like. John stated:

My wife thinks because I can go to work every day that she can't compare it with her arthritis, it's almost like I don't have anything. I shouldn't be tired. I oughta be able to go work 8 hours a day and then come home and work in the yard 8 hours a day. She doesn't believe it's anything compared to her arthritis. I talk to the people I work with about it. I really don't think they understand it . . . I don't know if she (his daughter) thinks there's something wrong with me or agrees with her mother and just thinks I'm just lazy. I think my mother actually thought I was sick and it did amount to something you know, I think my dad does.

Supported

Some of the participants felt supported by their family and friends in response to their illness. Beth simply answered the question with “supportive.” Jill responded with, “I guess with the right kind of attention and sympathy, especially as we get older.”

No Support

Only one participant felt no support. When asked about the response of family and friends Sara answered, “Rough, because it doesn’t affect the way you look. They’re not to understanding because you don’t look ill. They look at you and think you don’t look sick to me.”

Overall, most participants felt some type of a mixed response from others in regards to their fibromyalgia. A few participants perceived friends to be more supportive than family. Some admitted to feeling supported whereas only one felt no support.

Perceived Response of Medical Practitioners

There were many different responses and themes that emerged when participants spoke about their perceived responses of the medical community to their FM. The most common answers were the experience of a bad response, a lack of belief or understanding regarding fibromyalgia, or the lack of any treatment plan or adequate response by medical practitioners. Many believed they had a more positive response from specialists outside of their primary care physician. Several believed that now they had a positive response from their current medical practitioner. Some perceived a negative response when they believed that medical practitioners only focused on medicating them. Some

participants talked about the difficulty in finding a medical practitioner in their area who would treat their fibromyalgia. One participant thought the response from medical practitioners is better than it used to be.

All participants experienced some type of negative response from medical practitioners. Several believed that some medical practitioners did not believe in their illness or lacked an understanding of their condition. Several participants commented on the lack of knowledge they perceived certain medical practitioners to have in regards to fibromyalgia. A few believed certain medical practitioners did not listen to them or were not willing to work with them in regards to their treatment. A few thought certain medical practitioners only wanted to push medication. Some described their difficulty in finding medical practitioners to treat their illness. The following section will break down what was considered a negative response into their respective categories.

Lack of Belief or Understanding

Amy described negative experiences with medical practitioners as, “medical, I don’t think they’re there yet. I don’t know that all of them even believe it is a condition . . . I don’t think any of them really understand it and I don’t think they understand the disease or know.” John stated that he did not know if his general practitioner believed he had anything. He described his experience with medical practitioners:

I gave up on goin to see them. I think they got tired of me coming to see them with my ailments because about all they wanted to do was get you treated for depression . . . I don’t really see where they felt there was really anything they could do about it for anything that was specific to them. If you didn’t have a

disease where tests showed up that there was some protocol for treating it they uh you know they run blood work and call you back and say everybody wishes they had blood work as good as yours. I get tired of feeling bad, going, and having blood work done and stuff and getting called and hearing how wonderful it is you know . . . I know my first doctor I had when I first got sick just plain didn't believe in it . . . The next doctor I went to I think he probably believed it but some of the people in his office didn't really I don't think. When the Nurse Practitioner, she was that's all there is, nothing we can do for you, just buck up, tough it out.

Tanya went through a lengthy process to receive her diagnosis. This is the story of how she was eventually diagnosed which exemplifies to her a lack of understanding:

I had gone to the doctor because my arms hurt so bad. At that time, I was typing non-stop. Again, using the forearm, they did an EMG and said I didn't have carpal tunnel so I just lived with the pain because they said there's nothing wrong with you . . . I kept having problems, kept having problems so the guy just did surgery on both my wrists, said I had carpal tunnel. The pain didn't go away and it was again when I used, clenched those muscles in my forearms. So then they decided I wasn't getting circulation to my arms this hand and arm surgeon. So, then they took out a rib on each side separately because one time they collapsed my lung and if they did that on both I would die. So I had to have a chest tube and all that. Still the pain didn't go away but it wasn't constant so you tell someone your arms hurt. You might go to the doctor well they don't hurt today you know. I mean it's just and nobody got it, nobody got it til I went to someone

said you know you might have Rheumatoid Arthritis. So I went to (a Rheumatologist) and I explained everything as I'm explaining it to you and he brought me a pamphlet on fibromyalgia. It should of said, my pamphlet, because it was my entire life, every single thing, I felt like I wrote it . . . I lived a lot of years thinking why do my arms hurt all the time and nobody getting it.

Holly experienced a negative response from a Neurologist who told her there was no such thing as fibromyalgia. She stated that, "anytime I have to go see a specialist for anything it is always Russian Roulette if you will. I told you about the Neurologist's response. It's very frustrating."

Lack of Knowledge Regarding Fibromyalgia

Several participants believed their medical practitioners lacked knowledge regarding their illness. Most found this upsetting and some thought their practitioners were not even interested in learning more about it. The following will depict what these experiences have been like for them.

Sara described an experience where her primary doctor prescribed Lyrica for her fibromyalgia but the dose was incorrect. When she went to a pain clinic they told her she was not taking enough of the medication for it to do anything. According to Sara, "the doctor at the pain clinic was very understanding and seemed to have a whole lot more knowledge about it." Mary had an experience with her primary physician that she regarded as negative. Mary stated, "I remember asking one question and I asked him if there's anything new out about it and he kinda, he said well, look it up on the internet." When talking about her primary physician Mary also disclosed, "it doesn't seem like he's

interested in learning more about it. If I had a patient with a certain illness I would at least want to know a little more about it I think. I've gone to him for four years but I don't, most of the other doctors don't either." When asked about the response from medical practitioners, Jill stated, "I believe there could be more." Beth described a mixed response from medical practitioners. She stated, "I view a lot of the doctors as quacks."

Lack of Listening or Willingness to Work Together

Cindy implied that a lack of listening and willingness to work with her by trying other treatment approaches such as natural supplements was also a negative response. Amy described the response of medical practitioners as "very poor at best." When asked to elaborate she stated, "I think they reach a point where they don't wanna hear it." She felt brushed off when she told her doctor she was experiencing bad side effects from a medication they prescribed for her fibromyalgia symptoms. She described their response as, "well, that's the side effect . . . Initially I follow through and I come back and I tell you this makes me feel worse and you tell me that's a side effect I have to learn to live with." She admitted to feeling "angry that there is not a willingness to listen . . . The medications they give you affect fibromyalgia." Sara described the lack of listening she experienced by an Orthopedic Practitioner, "My orthopedic man said well we just don't know where it comes from or what to do for it. He just sort of brushed me off and we don't know so." Mary felt a lack of willingness to work together when she asked her doctor for a sleep test and was told she did not need one. One day she got the physician's assistant and was told that she needed a sleep test. The sleep test confirmed she had sleep apnea. She also got her fibromyalgia diagnosis from the physician's assistant and when

speaking about her primary care physician she said, “but I don’t think he really believes that (that she has fibromyalgia).” Mary also stated, “I don’t think they really understand it and I don’t think they’re on their way to understanding it.”

Medicate Only and Push for Medication

Cindy disclosed that her first medical doctor “wanted to medicate only.” She perceived this as a negative response. Amy also felt a push to take medication. She indicated, “They always wanna push the new (medication). Is there anything natural that would work?” John was frustrated with the medical community as he felt their only response to his fibromyalgia was to medicate him for depression.

Difficulty in Finding a Medical Practitioner

Some participants experienced difficulty in finding a medical practitioner in their area to treat their fibromyalgia. Jill described this process for her:

This last week my doctor tried to get an appointment for me with a doctor in this area who used to treat women and men with fibromyalgia and he doesn’t do it anymore . . . maybe insurance is not up to paying for specialists, specialized services for fibromyalgia, it’s not that recognized yet. So that’s frustrating. So there’s not treatment plans for us yet except for medication.

Holly drives a considerable distance to see her Rheumatologist. She explained this:

The Rheumatologist I see is absolutely wonderful . . . I drive (far) to see him because when I was diagnosed and I started calling, you know the doctor at the (Cleveland) Clinic that diagnosed me said you need to find someone who will

have some knowledge about this and who is willing to work with you. So I started calling all the Rheumatologists in (her area) and I heard from every single one of them, no, we don't deal with that.

Many participants spoke of positive responses they experienced from medical practitioners in regards to their fibromyalgia. Specialists, such as Rheumatologists, were perceived by many as responding more positively than general medical practitioners. For several participants, feeling understood was the main component of a perceived positive experience. A few did have positive experiences with their general medical practitioner as well. Two participants believed the response from medical practitioners was improving with time. One participant did not perceive any positive response from medical practitioners. For another participant, the only positive response regarding the medical community he perceived was that he felt his Rheumatologist believed in his illness. This section will describe the positive responses participants perceived from medical practitioners.

Positive Response from Specialists

The most common positive response by many participants was a good experience with a specialist. Cindy stated she was “very happy” with her Rheumatologist. A main point for Cindy in perceiving her Rheumatologist in a positive light was his willingness to work with her and to try natural remedies. She contrasted this with what she perceived as a negative response from her first medical practitioner who wanted to focus on medications only. Mary also perceived her experience with her Rheumatologist as positive. According to Mary, “I did go to a Rheumatologist and he was real

understanding.” Tanya described her experience with a Chiropractor as positive: “The Chiropractor I go to is all about it, like I said I was on a billboard for it.” Sara described her positive experience with a pain clinic as, “they were very understanding.” This clinic helped adjust her medication so she was taken the recommended dose for fibromyalgia patients. According to Sara, “I would say the doctor at the Pain Clinic was very understanding and seemed to have a whole lot more knowledge about it.” Holly described her Rheumatologist as, “absolutely wonderful.” Beth also sees a Rheumatologist who she described as “excellent, very patient, very understanding. They’ll do every test under the sun to help you and it’s like they understand.”

Understanding

For several participants, feeling understood was an important contributor in terms of a positive experience with the medical community. Holly described her experience with the primary care doctor she now sees as positive because he is “very understanding.” Mary’s experience with a Rheumatologist was positive as “he was real understanding.” Sara’s experience at a Pain Clinic was positive because “they were very understanding.” Beth perceived her Rheumatologist in a positive light because he was “understanding.” It appears when fibromyalgia patients feel understood by their medical practitioner they perceive the interaction positively.

Positive Response from General/Primary Medical Practitioner

A few participants perceived a positive response from their General/Primary Medical Practitioner. According to Cindy, “The physician I have now, or primary. . . I

am very happy with.” Holly views her “primary care doctor” as “very understanding and very wonderful as well.” Tanya also views her primary doctor as “supportive” and stated that “he’ll try stuff but everything he suggests I’ve tried.”

Medical Practitioners as Improving

Some participants thought the response from medical practitioners in regards to their fibromyalgia was improving. When asked how she perceived the response of medical practitioners to her illness Jill answered, “Better, better than prior. Better now than early on. I’m not afraid at all to now walk into a doctor and say that I have fibromyalgia...it used to be, you have what?” Similarly, Tanya commented that her general medical practitioner’s knowledge regarding her illness was improving. Tanya stated, “I think he’s learning about it cause he’ll say well you know I’m hearing more and more about it, learning more about it.”

Participants perceived responses from medical practitioners in regards to their illness varied. There were more negative impressions than positive. Negative conceptions emerged when participants thought medical practitioners did not believe in fibromyalgia, lacked an understanding of what it is like to have the illness, did not listen to them or want to work with them, lacked knowledge about fibromyalgia, or focused solely on medication as treatment. Another response considered negative was the difficulty some experienced in finding a medical practitioner to treat their illness. Participants sensed more positive responses from specialists, particularly Rheumatologists, a Chiropractor, and a Pain Clinic. A few participants recognized positive responses from their general medical practitioner. It appeared the notion of

understanding was an important contributor to a positive experience. Some participants believed the response from medical practitioners in regards to their illness was improving with time.

Achieving Support

Question 4: How do FM patients describe their experiences achieving support from friends, co-workers, medical practitioners, and family?

Participants had varied answers when asked about achieving support from others. Many felt supported by family. A lack of support from the medical community was felt by several. A few commented on negative experiences with their supervisor at work in regards to achieving support for their illness. No support from family was felt by a few. Some admitted to not sharing their illness with co-workers. One participant indicated that it was frustrating trying to achieve support from anyone. One participant did not have any family and lived alone, therefore, only commented on her experience achieving support from the medical community. This section will elaborate on these responses.

Positive Support from Family

Several participants disclosed feeling supported by their family. Cindy stated, “The support from my family has been wonderful.” Kerri indicated that she felt, “comfortable with the support I have from my family. I don’t feel like I’m off on my own.” Amy also believed she was supported by her family. When talking about her family Tanya commented, “I’ve definitely gotten support I think. Over the years they’ve just seen the difference in my, I’m a super happy bubbly person so if I’m quiet or down

in the dumps at all, tired a lot, and I have been cause my arms hurt so they, they know.”

Beth described the support she receives from her family as “excellent.”

Lack of Support from Medical Community

Achieving support from the medical community was not a positive experience for several participants. According to Amy, “members of the medical community, I would say no, there isn’t anything there.” She encouraged doctors to “listen to the person who has it, it’s different for everybody.” Sara had somewhat of a mixed response as she stated, “But the medical, they’ve been understanding. I guess they’re doing the best they can, which isn’t great.” John has not felt supported from the medical community. He described this as, “my regular doctors are can’t say I’ve gotten anything from them . . . I’ve went and seen a number of different Psychiatrists and Psychologists and they seem to apart from prescribing medicine, they don’t really have anything that helps.” He initially found his Rheumatologist supportive but stated that now, “she just works a tremendous amount of hours I think is one reason why you can’t hardly get to see her now. If you had an appointment in the afternoon you’re lible to be there at nine, ten o’clock at night.” Beth indicated that “certain doctors are great . . . others outside of that I wouldn’t waste my time or my breath.”

Some participants would like the medical community to respond to their illness by learning more about it and keeping them apprised of any new treatments. Mary would like doctors to “become more knowledgeable about it” and to “keep an eye out and see if something new comes out.” Beth would like for doctors to work harder in figuring out what causes or triggers fibromyalgia for each person.

Lack of Support from Supervisors

A few participants talked about the lack of support or understanding they received from supervisors at work. Beth indicated that she did not feel support from her supervisors at work and is now on medical disability. Amy sums her experience achieving no support from her supervisor:

I did expect more support from management. When you are up front about, I have this condition and especially for me when I worked in a division that dealt with disabilities I expected a little more support . . . I expected to be able to say, today is a really bad day. I may not get everything done. I am working at it the best that I can. And it was like if you can't do what we need you to do, we don't need you. And there was just no understanding whatsoever and when you're a person who has 19 years in and have never missed a day that you didn't have coming. It wasn't like I was asking for a leave of absence . . . I had one particular bad month and I think I missed three days. I was called in and written up and it was like you work for the division of students with disabilities.

John works a lot of overtime and stated that his doctors and family members tell him to "take time off, you work too much you know." When he attempts to take time off he feels hassled by his supervisor. When talking about this John stated:

I finally got so tired out feeling so bad in the spring I put in for one of the family leave so your absence will be excused so you won't get hassled all the time about missin a day. I mean I don't miss that many days anyway. I am tired of hearin about it. When you're working seven days a week and at least five or six double

shifts a month and they're yelling because you take a day off you know it's. So, I finally put in for one of those family medical leaves.

Lack of Support from Family

Feeling no support from family members was reported by a few participants. Mary disclosed that none of her family members provide support when it comes to her illness. Jill indicated that she received support from her family only up to a point. She related this to a societal problem:

I think this is a me society. I don't think we live in a culture today that really gives a lot to neighbors and family like we used to. . . My son in law says to me just last night, well you just got to deal with it mom. Thanks!

When considering support from family members John indicated a lack of support by stating, "it's hard for me to get any compassion from anybody when I work as many hours as I do."

Did Not Disclose Illness to Co-workers

Some participants did not disclose to their co-workers that they had an illness, therefore, they did not have any experiences in terms of achieving support from them. The commonality here lies in the fact they chose not to disclose their illness. According to Cindy, "the support from my co-workers, they didn't know about it." Amy did not expect support from co-workers as indicated by her response: "I was never the type to go into my personal life. Personal life is personal life and work is work. So, I didn't expect that from co-workers."

No Support

Holly used the term “frustrating” to describe what it has been like for her in terms of achieving support overall. Holly explains her answer:

If you had received a diagnosis of diabetes or heart disease or just about anything else people would be very oh wow. But when you say fibromyalgia they’ve heard so many myths and so much mis-information or else they don’t know anything about it and it just doesn’t seem to them like it’s real and so trying to get everybody it’s just tiring having to explain repetitively why. Why this or why that or what is it and or sometimes to even have people say you know roll their eyes. Oh yeah, that I hate, the eye rolling.

Overall, achieving support from others had mixed results as only two participants felt supported overall and one felt no support overall. The other participants had different answers based on who they were talking about. The mixed results indicated that for some support was felt by family whereas for others it was not. Those who chose to comment on members of the medical community had negative experiences achieving support. A few participants also talked about negative experiences they encountered trying to achieve support from supervisors at work.

Type-A Personality Structure

Participants were not asked about personality style or previous and/or current activity level. An emerging finding was that several participants described characteristics of pre-illness personality traits that could perhaps play a role in fibromyalgia. Almost all

participants described what may be a Type-A personality structure, at least the over ambitious orientation and perfectionism aspects, with one participant even using “Type-A” to describe herself. Since the seminal work of Friedman and Rosenman (1974) there has been much research on Type-A personality structure. Based on this research, “there are some universally agreed upon characteristics of the Type-A individual that add up to a generally ambitious orientation to life” (Watson, Minzenmayer, & Bowler, 2006, p. 1111). Karren, Hafen, Smith, and Frandsen (2001) summarize the Type-A personality traits that have been supported substantially by research as: original free-floating hostility, extremes of aggression, strong sense of time urgency, achievement striving as a result of insecurity of status, and drive to self-destruction. Rayburn & Rayburn (1996) cite impatience and competitiveness as secondary characteristics of Type-A behavior. Type-A individuals have also been characterized as having a strong need for self-appraisal (Watson, Minzenmayer, & Bowler, 2006). Flett, Hewitt, Blankenstein, & Dynin (1994) describe Type-A personalities as showing a higher desire for self-oriented perfectionism than do Type-B’s.

Tanya described her personality style as Type-A:

It can be nice out and you wanna be outside and you wanna be doing stuff and you think I can’t do it or I just wanna do something. I’m home alone all day, everybody is gone and I have to wait to empty my car out or I have to wait to do something because I can’t do it because my arms hurt or again if you’re a Type-A personality where you’re non-stop, I don’t sit. I don’t sit and watch TV, not very well anyways. I’m constantly on the go so that takes a person, like me totally out of my element and makes me have to sit and it’s difficult.

Cindy described what appears to be a very ambitious orientation to life prior to fibromyalgia:

I used to be on top of it. I knew exactly what my kids were wearing to school. I knew what doctors appointments, what times, what medications. My late husband passed away and he was on 30 different medications. I knew what each dose number was, how often he had to take them, what the side effects were, all that and it's like I can't process or remember anymore. When I was being a caregiver, I used to do it all. . . I was one of their best workers. I knew I was a good worker because of what my standards were. . . I ran and maintained several programs for church, and Easter baskets, on top of working, decorating cakes, running a household, and taking care of children. . . (After her diagnosis of fm) I had tried to work and continued to work until it was just not possible anymore.

Kerri described her pre-fibromyalgia life as "I tended to be a workaholic and I did not get more than like 5 or 6 hours of sleep a night. I had a family and I was just on the go all the time and didn't get enough rest." Kerri continues to be active and talked about recently painting all the rooms in her house. Holly stated that prior to fibromyalgia she "used to be able to juggle quite a few balls and quite a few different pieces of information at the same time and manage it." Mary described her life before she got fibromyalgia as very busy and over-involved in numerous activities. She stated, "before I got it, I was involved almost every evening with something." She reported she always worked and one of the challenging things about her fibromyalgia was learning to pace herself and "to stop when your body says stop." John continues to work a tremendous amount of overtime. He described this as:

Everybody tells me I work too much to start with. Work too many hours. It's hard for me to get any compassion from anybody when I work as many hours as I work. I've got a job that would pay about \$65,000 a year if you work 40 hours a week and I made \$175,000 last year, so that was a lot of overtime.

Amy was a hard worker pre-fm and stated she never missed a day of work in 19 years, while at the same time running a household, being very active in outside organizations, and maintaining numerous friendships. She indicated she had very high standards for herself. She disclosed that "keeping a home now is far below what my standards were." Beth worked a full time job and ran her own business prior to getting fibromyalgia. She re-modeled several homes and helped her children work on their homes. She has a very difficult time with the confines of her illness. She described this by stating, "you take somebody that used to work and who you could never keep down and all a sudden they're sittin around getting fat, it's depressing!"

Summary

Overall, ten participants were interviewed regarding their lived experiences with FM. The first part of this chapter provided a description of each participant case. Individual understandings of the cause of their illness were also reported.

The second part of the findings provided the results from phenomenological analysis considering all participant illness experiences. The first section of this part described participant experiences and understandings of their illness. The common experiences that emerged were: Feelings of pain, exhaustion, frustration, and depression; the experience of cognitive difficulties; the experience of un-predictable and changing

symptoms; the experience of not looking sick; and the experience of not being understood. Participants understood their illness as one that is invisible to others and one that is constantly changing. The second section of this part focused on describing how the unknown origin of FM impacts participants. The unclear cause had either a continuing negative impact or a negative impact at the beginning of one's illness course. Unknown etiology did not appear to be the most concerning or troubling aspect of FM for these participants. Participants in this study focused more on the above mentioned experiences and the response of others to their illness. The third section of this part described participant perceived responses of others to their illness. In this study, friends appeared to be more supportive than family or members of the medical community. Many felt support by certain people and not others. In terms of the medical community, specialists were perceived as having the best response. It seems the response from medical practitioners is improving as some reported positive experiences now whereas they did not have any in the past. The response from co-workers was hardly addressed in this study as many chose not to disclose their illness to fellow employees or were no longer working. The fourth part focused on experiences achieving support in regards to FM. Experiences achieving support had mixed results based on who was being considered. Overall, most had achieved some support from close friends, significant others, and some members of the medical community. Some of these same participants and others felt they had achieved little to no support from certain family members, significant others, and members of the medical community. The idea is that support varies depending on the person considered. The last section of this chapter mentioned an emerging finding not directly solicited. Almost all participants talked about or

described an overly ambitious orientation to life which upon further exploration or research may match the Type-A personality structure.

CHAPTER V

DISCUSSION

This chapter is divided into four sections. The first section consists of a discussion of the implications of the findings as they apply to the research questions. The second section provides a discussion of the findings as they apply to counseling psychologists working with patients who have fibromyalgia. Following this, section three provides a discussion of the limitations and advantages of this exploratory study, including issues of validity and reliability. Finally, recommendations for future research are provided.

Patient's Experience and Understanding of their Illness

There were many commonalities in participant description of the experience of fibromyalgia. The findings in this study affirmed that pain is very much a part of the experience of living with fibromyalgia. Fibromyalgia was described by all 10 participants as a painful condition, with variance occurring in terms of pain location and duration. Numerous studies indicate cognitive difficulty as a prominent symptom in FM (Clauw & Crofford, 2003; Dick, Verrier, Harker, & Rashiq, 2008; Leurding, Weigand, Bogdahn, & Schmidt-Wilcke, 2008; Sephton et al., 2003). As is consistent with these findings, participants in this study either described or experienced cognitive difficulties. Sleep disturbance is cited as one of the more common symptoms of fibromyalgia (Clauw & Crofford, 2003; Linebarger et al., 2007; Moldofsky, 2008). Many participants in this study talked about their experience of persistent exhaustion in relation to their fibromyalgia. The findings supported illness uncertainty (Recih & Olmstead, 2007) as

common in the lived experience of fibromyalgia. Many highlighted the fact that their symptoms were un-predictable and changing which meant living with week-to-week or even moment-to-moment uncertainty. Others mentioned frustration in not knowing if certain symptoms were part of their fibromyalgia or the result of something else. Most participants used some form of the word frustration to capture what fibromyalgia is like for them. As is consistent with quality of life studies on fibromyalgia (Arnold et al., 2008; Cunningham, & Jillings, 2006, Asbring, & Narvanen, 2002;; Hallberg, & Carlsson, 2000; Sturge-Jacobs, 2002) almost all participants found fibromyalgia to be life-altering as many could no longer engage in simple everyday tasks or activities previously enjoyed. Participants experienced a lack of understanding from others in regards to their illness. Several commented on the fact that people with fibromyalgia do not have any physical markings which therefore take away from the credibility of their illness and limitations. A strong association between depression and FM is cited in the literature (Artic & Toraman, 2002; Thieme, Turk, & Flor, 2004). Results from this study showed depression was commonly experienced due to the above mentioned descriptors of the illness. For the participants in this study, the experience of fibromyalgia was physically and emotionally painful as well as life-altering.

Impact of Unclear Origin on Patient Perceptions and Feelings

Only one participant knew the cause of her illness. The other nine speculated as to the cause but could not come up with a definitive origin. According to Reich et al. (2006) research implies that illness uncertainty, including unknown etiology, may be a significant factor in understanding patients with FM in terms of their behavior and

physical and mental functioning. Johnson, Zautra, and Davis (2006) concluded that illness uncertainty had a negative influence on coping. According to Tumlin (2001), “Those who do not understand the cause of their condition report more pain and distress than those who believe they do” (p. 1278). Frankly, I was surprised that in direct contrast to the literature, several participants were not bothered by the unknown cause of their illness but instead focused their energy on coping. These participants were the ones who had their diagnosis the longest which may have played a mediating role in this attitude. Several even commented that they no longer focus on the cause implying there was a time when this was an issue for them. Findings did reveal that the unknown origin of fibromyalgia was frustrating for some participants and they wanted answers. Many conducted their own research in an attempt to find these answers. Overall, the participants in this study had thought about or attempted to research a cause for their illness. Those diagnosed longer appeared to have shifted their focus from discovery to coping. It appears length of diagnosis may play a role in decreasing the negative influence of illness uncertainty as it relates to unknown etiology.

Perceived Response to FM

The findings of this study revealed a mixed response in how those with fibromyalgia perceived the response of family and friends to their illness. Some felt support from friends but not family. For most, the perceived response varied depending on who was considered. Only one participant felt supported entirely and likewise only one participant felt no support at all.

All 10 participants in this study experienced some type of negative response from medical practitioners to their illness. Many perceived a lack of belief or understanding from members of the medical community. Some participants were even told by various medical practitioners that they did not believe in fibromyalgia. Findings support frustration in proving the existence of one's fibromyalgia illness (Barker, 2002). Participants did not feel listened to or taken seriously by many medical practitioners. Many were frustrated that the only treatment plan for fibromyalgia from many practitioners was in the form of medication. Participants perceived a lack of knowledge regarding their illness from many members of the medical community. Others experienced great difficulty in finding a medical practitioner in their area who was willing to treat their condition. This study did demonstrate that the perceived response to fibromyalgia by the medical community appears to be improving. Several participants had positive experiences with specialists whereas others are now experiencing positive responses from their current primary care physician.

Experiences Achieving Support

In this study, participants had mixed responses when describing what it has been like for them in terms of achieving support from family, friends, co-workers, and members of the medical community. Several participants felt support from family whereas a few felt no support from family. Several described a perceived lack of support from the medical community. One participant felt no support from anyone. A common response supported in the literature (Barker, 2002) was frustration in having to explain their illness and symptoms repeatedly to others still without any felt sense of

understanding or support by others. For those participants who chose to comment on the work environment this study revealed no perceived support. Some participants chose to keep their illness private whereas those who did share with management did not experience a positive response. They believed their fibromyalgia was not viewed as a reason to take off work or to adjust one's schedule. Overall, participants expressed some positive and some negative perceptions of what it is like for them to achieve support from others in response to their fibromyalgia.

There were many commonalities in terms of what participants want from others in response to their illness. All but one participant cited understanding. Most want others to understand that even though they do not look sick, they have an illness that imposes certain limitations. In support of the findings of Haugli, Stand, & Finset (2004), who found that what patients want most from medical doctors is a diagnosis that did not imply that the etiology of the pain was psychological, participants in this study want recognition by both the medical community and others that fibromyalgia is a real condition. Some would like for members of the medical community to learn more about the illness and to keep them abreast of new treatments. It appears that patients with fibromyalgia are not seeking sympathy but assistance with tasks they can no longer do. Overall, the findings from this study revealed understanding and acknowledgement as the most sought after responses to one's illness.

Implications for Counseling Psychologists

This section incorporates the findings of this study with chronic pain psychotherapy research to provide treatment suggestions for counseling psychologists

choosing to work with clients who have fibromyalgia. An overview of general counseling skills and their application to fibromyalgia clients will be presented. Following this, specific treatment approaches, resources, and theoretical practices effective with chronic pain patients will be highlighted.

General Counseling Skills

A counseling psychologist electing to work with clients with FM is encouraged to review the chronic pain/fibromyalgia treatment literature for specific effective practice with FM patients. A meta analysis study by Hoffman, Papas, Chatkoff, and Kerns (2007) found that general supportive counseling skills were helpful in reducing pain intensity and for clients coping with chronic pain. Counseling psychologists already possess the necessary general counseling skills to be effective clinicians for this population but must also combine this with a research background in chronic pain treatment and practice.

The participants in this study frequently talked about their desire to be understood. Counseling psychologists are equipped to provide such understanding to clients with fibromyalgia. Basic counseling skills such as active listening, summarizing, and paraphrasing are effective tools to help the counselor gain a deeper understanding of what fibromyalgia is like for their client. As exemplified in this study, the experience of fibromyalgia has many similarities but is also different for each client. Therefore, the counseling psychologist is encouraged to understand the illness from the perspective of each individual client.

Another finding from this study indicates that participants with fibromyalgia were seeking empathy and assistance not sympathy or pity. A counseling psychologist already

possesses the tools to establish and communicate empathic concern and understanding. Relying on their skills to empathize with clients, counseling psychologists are equipped to provide one of the most important elements necessary to be effective with clients who have fibromyalgia.

Many participants in this study did not feel supported by their family or significant others. Counseling psychologists can utilize family therapy in their work with clients with fibromyalgia. According to Lewandowski, Morris, Draucker, and Risko (2007) attention to the family dynamics of clients with chronic pain is needed as chronic pain affects numerous aspects of family functioning. Family therapy approaches that have been utilized with clients in chronic pain include behavioral, cognitive behavioral relational, and family systems approaches (Kerns & Otis, 2003; Romano, Jensen, Turner, Good, & Hope, 2000). Counseling psychologists can help clients increase their support network by suggesting an on-line or in-person fibromyalgia support group. Research shows that participation in on-line support groups can be very helpful in increasing support and the overall empowerment of chronic pain patients (van uden-kraan, drossaert, taal, seydel, & van de laar, 2009). The National Fibromyalgia Association (2010) has a web site that lists their endorsed support groups by geographical location.

Findings from this study revealed that many participants were frustrated with the medical communities push to medicate without offering other treatment options. A few participants talked about their desire to try more natural approaches for the treatment of their fibromyalgia. Research (Laswon, 2008) indicates that the treatment of fibromyalgia requires both pharmacological and non-pharmacological management. A counseling psychologist working with clients with FM should be prepared to assist with both types

of treatments. Many psychotropic medications have wide clinical applications in the management of chronic pain (Cochran, 2007). A counseling psychologist working with FM clients should have knowledge of psychotropic medications including their side effects and uses to help clients with fibromyalgia make informed choices whether to use them or not. If a client elects to try non-medicinal options or to include them with medication, counseling psychologists have a wide array of tools and techniques to offer. Guided imagery and hypnosis, increasing coping skills, relaxation training, meditation, and biofeedback have all been implicated as effective in treating chronic pain (Goldenberg et al., 2008; Syrjala & Abrams, 2002).

Participants in this study all elaborated on the life altering nature of their illness. Many had to give up physical activities they once enjoyed. According to Waddell (2004) people suffering from chronic pain often reduce their physical activity, which contributes to physical disability. Aerobic exercise and water-based physical activities have demonstrated improvements in overall well-being, sleep, psychological function, and pain-pressure threshold in patients with fibromyalgia (Busch et al., 2008; Jones et al 2006; Maquet et al., 2007). Unfortunately, people with fibromyalgia often eliminate most physical activity from their life as they initially cause more pain and symptom severity. Counseling psychologists can use their resources to intervene with behavioral plans that help clients work up to higher levels of physical activity and to learn when to take breaks in order to prevent flare-ups of symptoms. Education on what types of exercise that have been shown to be beneficial can also help as exercise that strengthens the skeletal muscles, such as stretching, is considered to be of great importance for patients with FM (Busch et al., 2008).

Specific Treatment Approaches with Chronic Pain Patients

In addition to basic counseling skills, there are some issues specific to the treatment of chronic pain counseling psychologists who choose to work with clients with FM should be aware of. This section will highlight these issues which should be explored in greater depth before treating a client with FM/chronic pain. Resources providing more detailed information will also be provided.

There are billing codes, introduced in 2002, that allow counselors to bill and receive reimbursement for client's adjusting to physical health diagnoses (APA, 2002). A counseling psychologist should make note of these as insurance may cover care for some clients with fibromyalgia. As noted by Tumlin (2001) chronic pain patients often have few financial resources for psychotherapy due to lost income and costly medical bills. Counseling psychologist may need to offer sliding fee scales in order to make counseling a possibility for certain clients with fibromyalgia.

As consistent with the findings of this study, Otis (2007) reports that chronic pain clients have a desire to understand what is happening to their body physically in addition to receiving support in dealing with their pain. Gatchel et al. (2007) asserts that mental health counselors need to understand the biology of pain when working with chronic pain patients. The biological understanding of chronic pain falls outside of the scope of this study, however; there are several easy to read condensed versions of the pain process. Farrugia and Fetter (2009) offer a journal article with a three page summary of the biological processes of pain.

Cognitive-behavioral therapy has received the most attention in the literature in terms of its effectiveness in the treatment of chronic pain (Thorn 2004; Turk & Gatchel,

2002). The goals of cognitive-behavioral therapy are to solve problems relating to maladaptive thoughts, emotions, and behaviors by process of a goal-oriented, systematic procedure (Turk, 2002). Specifically with chronic pain patients, Gatchel (2005) states that the cognitive-behavioral therapy interventions empirically shown to be effective include cognitive restructuring, problem-solving, techniques aimed at increasing coping skills, reinterpretation of pain sensations, attention diversion, and focusing on the sensory qualities of the pain as a management strategy.

There are several resources available to assist a counseling psychologist in conceptualizing the client with chronic pain. Butler (2000) provides specific questions to ask in order to assess the consequences of the illness. Thorn (2004) offers an approach specific to chronic pain patients to assist in case conceptualization. For counseling psychologists looking for a more detailed approach, Johnson and Webster (2002) have written a treatment manual for therapist working with clients experiencing chronic illness and pain. This manual reviews the stages of adjustment for persons experiencing chronic illness and provides treatment tools such as handouts, in-session activities, and homework assignments.

In summary, a counseling psychologist's general counseling skills can be effective in working with clients with FM. A counseling psychologist should also have knowledge of the chronic pain and FM treatment literature. An overview of the biological pain process is necessary along with knowledge of psychotropic medication. A counseling psychologist should be prepared to work with medical providers in establishing an individualized treatment program for the client with FM.

Limitations

The qualitative design of this study provides some inherent limitations. As in all phenomenological studies, external validity is absent due to the exploratory nature of the study and the small sample size. Because of this, the results cannot be generalized as in a quantitative study. However, Lincoln and Guba (1985) propose the construct of transferability in replace of external validity when conducting qualitative research, in which the researcher should argue that her findings will be useful to others in similar situations with similar research questions or questions of practice.

Another limitation distinct to this study was the lack of participant diversity. All of the participants came from the Midwest region. Although this allowed for face to face in-depth interviews, it decreased variation between participants. All participants identified as “White” which may impact one’s personal experience with fibromyalgia as Gansky and Plesh (2007) reported that ethnic differences seem to exist in the experience of the pain of FM. Schaefer (2005) highlighted a coping difference between African American and Caucasian women as African American women were more likely to use their spiritual belief system than Caucasian women. All participants but one in this study was female and gender may also influence one’s experience with fibromyalgia. The age range of participants in this study was 43-86 years. This may have been limiting as there were no participants under the age of 43.

Participant variance in terms of length of diagnosis appears to be an important limitation. In this study length of diagnosis varied from 2 ½ years to 15 years. The phenomenon under investigation, illness uncertainty as it relates to unknown etiology,

may play a more significant role in the lives of those with fibromyalgia in the earlier years of their illness.

Another possible limitation of the study was the tape recorded interviews themselves. Participants appeared to be mindful of what they were saying when the tape recorder was on. Participants seemed more open in their descriptions of fibromyalgia and what it is like to achieve support when the tape recorder was off. This researcher attempted to capture these descriptions in self-memos written after each interview.

Validity and Reliability

Several attempts were made to increase the validity and reliability of the current study. The internal validity of this study was enhanced through the use of multiple methods of data collection; interviews, a questionnaire, and transcripts of interviews. This researcher has also been diagnosed with fibromyalgia. In an attempt to reduce research bias, I used the concept of bracketing, in which I set aside my own experiences, as much as possible, so as not to influence the study. According to Moustakas (1994) in research, this state is seldom perfectly achieved. Internal validity was strengthened by checking with participants' to ensure the transcript of their interview was an accurate reflection of what they intended to describe.

Another possible threat to validity and reliability comes from the fact that I was the only researcher working on the study, and thus it was more likely that my own assumptions and biases may limit reproducibility. As the sole researcher, things were done according to my perceptions rather than collectively through a research team.

Therefore, I may have unknowingly placed more emphasis on issues typical of my own illness experience.

Reliability was enhanced through the use of an interview guide, selection criteria based on length of diagnosis, and describing in detail the method of analysis. Internal reliability was enhanced through thick and often verbatim description of participant responses.

Recommendations for Further Research

This study attempted to discover what it is like for patients with fibromyalgia to experience an illness, focusing on one aspect of illness uncertainty, unknown etiology. Several participants in this study who had their diagnosis for six years or more, with the exception of one, were not bothered by the unknown origin. Those with a diagnosis of four years or less were troubled by the unknown cause. Some participants within the longer diagnosis category disclosed that the unknown origin of their illness used to be a concern for them. Future research exploring how length of diagnosis mediates this aspect of illness uncertainty and when and how the cognitive shift from cause to coping occurred is warranted.

A commonality among participants in this study was the description of pre-illness personality traits that could perhaps play a role in fibromyalgia. Almost all participants described what appears to be a Type-A personality, with one participant even using “Type-A” to describe herself. According to Johnson (2008) fibromyalgia is commonly viewed as a stress disorder. A quantitative study focusing on the prevalence of Type-A

personality structure in patients with fibromyalgia would serve well to explore whether this type of personality structure plays a role in the illness.

The findings of this study revealed that overall FM patients found the response of friends more supportive than family. According to a study by Jamison and Virts (1990) chronic pain patients who reported having non-supportive families tended to report more pain, relied more on medication, used more pain descriptors when describing their pain, and showed more emotional distress compared with pain patients coming from supportive families. These researchers contend that perceived support is an important factor in the treatment of chronic pain patients. A qualitative study detailing perceived supportive responses and how family could respond better might help therapists intervene more effectively in family work with FM patients. Furthermore, a quantitative study evaluating the effects of family education and support programs could demonstrate effective practices for increasing family support for those with fibromyalgia.

Conclusion

This study intended to explore unknown etiology as it pertains to illness uncertainty. Only a few participants in this study cited concern over the unknown cause of their illness. Those who had been diagnosed with fibromyalgia the longest reported that the unknown cause of their illness was no longer a troublesome aspect for them. These participants had shifted their focus to coping. Participants who had their diagnosis the least amount of time were still troubled by the unknown cause of their illness and focused on finding answers.

In conclusion, the results from this study support counseling psychologist efficacy in treating patients with fibromyalgia. Overall, the participants in this study want their illness experience to be understood and to be acknowledged. They are focused on increasing coping skills as well as their knowledge regarding their illness. Many described deficits in their support system and numerous negative experiences with medical practitioners. Counseling psychologists have the training to effectively address the abovementioned areas and to provide a more positive experience with a member from the helping profession.

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Appendix A
The Researcher's Story

The Researcher's Story

I was born in Vicksburg, Michigan. Growing up I was a very physically active child and participated in numerous sports. I played basketball and softball in high school and intra-mural sports in college. I enjoyed good health throughout my childhood and early adult years. I was very active not only in sports but also as a volunteer in my community.

After earning a Bachelor of Arts degree from a private liberal arts college, I worked as a youth specialist, counseling adjudicated youth, at a residential treatment facility. In this same agency, I was promoted to the role of family services counselor where I traveled throughout the state of Michigan, mostly to inner cities, conducting family counseling. During this time, I received a master's degree in social work. As part of my graduate school training, I worked as a medical social worker intern in a hospital setting. I was then promoted to a senior clinician at the residential facility. In this role, I supervised a treatment team and facilitated group therapy. After obtaining my license as a clinical social worker, I also started working part time as a counselor in a small private practice.

In 2003, I began experiencing persistent fatigue no matter how much sleep I got. Along with the tiredness came intense back pain. Everything in my life became very painful. I could no longer engage in the physical activities I once enjoyed. My primary medical doctor could not find anything wrong with me. I also started experiencing stomach pain and irritable bowel symptoms. I was given numerous tests and had blood-work done by several different doctors and specialists. During this time I was misdiagnosed with several conditions such as celiac disease, lupus, possible MS, and

various other auto-immune diseases. I saw a rheumatologist, a chiropractor, several general physicians, various specialists, and underwent physical therapy. Each one of these doctors proclaimed I had whatever their specialty was and that they could help. Nothing they prescribed ever helped. After years of intense pain and fatigue, I was finally told by a physician's assistant that I may have a condition called fibromyalgia. I then went to the Cleveland Clinic where my diagnosis of fibromyalgia was confirmed. I was offered a diagnosis but no treatment plan except to engage in some sort of physical activity daily and to accept that I would be in pain. I was surprised by the medical community's lack of knowledge regarding this illness. For example, I was prescribed Lyrica by a physician's assistant. My primary physician asked why I was taking it. I told him it was approved for fibromyalgia and he had to get a book out to verify that was correct. I found out about my illness through my own research. I even questioned whether I truly had fibromyalgia as I was given so many other wrong diagnoses. I was once told by a general practitioner that I could stop investigating my illness now as we are certain it is fibromyalgia. He seemed irritated that I was still trying to find out what was wrong with me. A year later this same doctor asked, are we sure this is fibro? I once asked my gynecologist what he thought about fibromyalgia, without telling him I had it, and he remarked that he did not believe in it and that those people always seem to have something. This entire process was very expensive and time consuming and I am still left with unanswered questions. I was initially relieved to finally have a diagnosis. This relief was short lived as fibromyalgia comes with no answers. This illness has no known etiology and no cure. To say fibromyalgia is frustrating is an under-statement. The most troublesome aspect of this illness for me is all the unknowns and uncertainties. The first

few years of this illness were the worst years of my life. I was offered no help or support except for a few referrals to counselors who had never heard of this illness or had no idea how to help one in chronic pain. This was also an expensive exercise in futility. I gave up looking for outside help and decided to instead try to be the help to others with this illness. This desire led to this specific research study as the unknown origin of my illness still remains a very troubling aspect for me.

Appendix B
Human Subjects Institutional
Review Board Letter

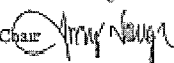
WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date March 31, 2010

To Alan Hovestadt, Principal Investigator
Samantha Wheeler, Student Investigator for dissertation

From Amy Naugle, Ph.D., Chair 

Re HSIRB Project Number 10-02-31

This letter will serve as confirmation that your research project titled "Exploring the Experiences of Living with a Controversial Illness in Patients with Fibromyalgia" has been approved under the expedited category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes to this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination March 31, 2011

Walwood Hall, Palmetto, MI 49836-3406
PHONE: 269/387-8293 FAX (REC): 387-8276

Appendix C

Consent Form

Consent form

Western Michigan University
Department of Counselor Education and Counseling Psychology (CECP)
Principal Investigator: Dr. Alan Hovestadt, Ed.D.
Student Investigator: Samantha L. Wheeler, LMSW, ACSW

You have been invited to participate in a research project entitled “Exploring the experiences of living with a controversial illness in patients with fibromyalgia.” This research is intended to study how patients with fibromyalgia experience their illness. This study is the dissertation project of Samantha L. Wheeler.

You will be asked to participate in the following manner:

- Completing a brief demographic questionnaire
- Participating in an audiotaped semi-structured interview lasting approximately 60 minutes

As in all research, there may be unforeseen risks to the participant. One potential risk of participation in this project is that you may experience discomfort or unease during the interview process; however, Samantha Wheeler is prepared to provide crisis counseling should you become significantly upset and she is prepared to make a referral if you need further counseling about this topic. You will be responsible for the cost of therapy if you choose to pursue it.

One way in which you may benefit from this activity is having the chance to talk about what it is like to experience your illness. Counseling psychologists and health care professionals may benefit from the knowledge that is gained from this research.

All of the information collected from you is confidential. That means your name will not appear on any papers on which this information is recorded. The forms will all be coded, and Samantha Wheeler will keep a separate master list with the names of participants and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. All other forms and tape recordings will be retained for at least three years in a locked file in the principal investigator’s office. All tapes and forms will be destroyed following the three year mark.

Any identifying information will be changed in the final report to protect your confidentiality.

You may refuse to participate or quit at any time during the study without prejudice or penalty. If you have any questions or concerns about this study, you may contact either Samantha Wheeler at (269) 420-2991 or Dr. Alan Hovestadt at (269) 387-5117. You may also contact the chair of the Human Subjects Institutional Review Board at (269)

Appendix D
Interview Guide

Interview Guide:

- Thank you for your participation in this study. Please remember that although I have received your signed consent form, your continued participation in this research project remains entirely voluntary. You may refuse to answer any given question at your discretion. You are free to discontinue your participation in this study with no negative repercussions whatsoever. Please also remember that this interview will be tape- recorded.

- I am interested in learning about how patients with fibromyalgia experience and understand their illness. In examining this process, I am particularly interested in how an illness with an unknown cause and one without physical markings affect one's understanding and opinion of the illness with particular focus on the response of others to the illness.
 - First of all, would you please tell me what it is like having fibromyalgia?
 - Do you know the cause of your illness? (if no, proceed to next question).
 - How does the un-known cause of your illness affect your views and feelings about it?
 - How do you perceive the response of family and friends to your illness?
 - How do you perceive the response of medical practitioners to your illness?
 - What has it been like in terms of achieving support from family, friends, co-workers, and members of the medical community?
 - What would you like the response from others to your illness to look like?

Appendix E
Demographic Questionnaire

7. What is your household annual income? _____
8. How long have you had your diagnosis of fibromyalgia? _____

Appendix F

Poster

Do you have **FIBROMYALGIA** or know someone who does?

As part of her doctoral dissertation project, Samantha Wheeler, in collaboration with Dr. Alan Hovestadt, is looking for research participants to interview regarding what it is like to experience fibromyalgia.

You will be asked to participate in the following ways:

- Complete a brief demographic questionnaire
- Participate in an audio-taped semi-structured interview (lasting approximately 60 minutes)

As a fibromyalgia sufferer, you can benefit from this research by helping to inform counselors and health practitioners of what it is like to experience your illness.

All of the information collected from you will remain confidential. All participation is voluntary and you may refuse to participate or quit at any time during the study without prejudice or penalty.

If you are interested in participating in this study please contact Samantha Wheeler at (269) 420-2991 or e-mail her at Samantha.l.wheeler@wmich.edu

Appendix G
Invitation to the Study

Invitation to the study

Western Michigan University

Department of Counselor Education and Counseling Psychology (CECP)

Principal Investigator: Dr. Alan Hovestadt, Ed.D.

Student Investigator: Samantha L. Wheeler, LMSW, ACSW

You have been invited to participate in a research project entitled “Exploring the Lived Experiences of Fibromyalgia Patients.” This research is intended to study how patients with fibromyalgia experience their illness. This study is the dissertation project of Samantha L. Wheeler.

You will be asked to participate in the following manner:

- Completing a brief demographic questionnaire
- Participating in an audiotaped semi-structured interview (lasting approximately 60 minutes)

All of the information collected from you is confidential. All participation is voluntary and you may refuse to participate or quit at any time during the study without prejudice or penalty. If you are interested in participating in this study please contact Samantha Wheeler at (269) 420-2991.