A WORKSHOP FOR MARRIAGE AND FAMILY THERAPISTS:
UNDERSTANDING FIBROMYALGIA SYNDROME

A graduate project submitted in partial fulfillment of the requirements
For the degree of Master of Science in Counseling,
Marriage and Family Therapy

By

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# Table of Contents

Signature Page.............................................................................................................. ii
Acknowledgements......................................................................................................... iii
Abstract............................................................................................................................... vi

Chapter I Introduction........................................................................................................... 1
   Statement of the Need/Problem....................................................................................... 1
   Purpose............................................................................................................................. 2
   Significance...................................................................................................................... 3
   Terminology.................................................................................................................... 3
   Overview of Remaining Chapters.................................................................................. 7

Chapter II Review of the Literature..................................................................................... 8
   Introduction.................................................................................................................... 8
   Fibromyalgia.................................................................................................................. 8
   Etiology............................................................................................................................ 9
   Characteristics............................................................................................................... 10
   History of Diagnosis...................................................................................................... 11
   Psychosocial Factors..................................................................................................... 16
   Psychological Factors.................................................................................................... 16
   Invisible Disability.......................................................................................................... 18
   Treatment...................................................................................................................... 19
      Pharmacotherapy....................................................................................................... 21
      Bowen Family System Theory.................................................................................. 31
      Emotional Exposure-Based Treatment..................................................................... 34
Cognitive Behavioral Therapy..............................................40

Chapter III Project Audience and Implementation Factors..........................43
  Introduction.............................................................................43
  Development of Project..........................................................43
  Intended Audience.................................................................44
  Personal Qualifications..........................................................44
  Environment and Equipment...................................................45
  Project Outline........................................................................45

Chapter IV Conclusion...............................................................47
  Summary..................................................................................47
  Discussion................................................................................48
  Future Work/Research..............................................................51
  References...............................................................................52
ABSTRACT

A WORKSHOP FOR MARRIAGE AND FAMILY THERAPISTS:
UNDERSTANDING FIBROMYALGIA SYNDROME

By

Michelle Lee Williams

Master of Science in Counseling,
Marriage and Family Therapy

The purpose of this project is to create a workshop that will educate Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists about fibromyalgia syndrome. Once educated, therapists would be able to recognize this medical condition and appropriately treat their therapy clients; they would dismiss labels such as somatization disorder, factitious disorder or malingering, for this population. In addition, they would be aware of and can assess for the high rates of depression and suicide risk associated with the diagnosis. In clients not yet diagnosed with fibromyalgia the educated therapist will potentially have the foresight to refer their clients to an appropriate medical doctor for evaluation and treatment. If the therapist is knowledgeable and prepared with the appropriate treatment options, in advance, for the obstacles that some with fibromyalgia face, their effectiveness for this population of client will improve. In addition, the relationship between the therapist and client diagnosed with fibromyalgia could strengthen as a result of the therapist taking the initiative to understand their client’s subjective reality.
“Strength does not come from physical capacity, it comes from an indomitable will”

Mohandas K. Gandhi

As stated in the Institutes of Medicine’s (IOM) study on the state of science regarding pain research and the care and education of those affected with pain, over 100 million American adults are affected with chronic pain. This is more than all those who are affected by heart disease, diabetes and cancer combined (Institute of Medicine [IOM], 2011). Fibromyalgia syndrome is one of the chronic pain conditions.

Statement of Need/Problem

There is evidence that many people with fibromyalgia also suffer from comorbid depression. Wolfe and Hawley (1998) found the lifetime depression rate for people with fibromyalgia to be between 20% and 86% with a median rate of 58%. They also found in their research that people with fibromyalgia consistently had higher rates of depression than the healthy control subjects as well as those with rheumatoid arthritis or other rheumatic diseases (1998).

Dreyer, Hendall, Danneskiold-Samsoe, Bartels and Bliddal (2010), found that the risk of death by suicide in women with fibromyalgia was 10 times higher than the standard population. This alarmingly high statistic for death by suicide for those with fibromyalgia is a significant problem. Therefore, there is a need for Marriage and Family
Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists to have an understanding of fibromyalgia syndrome in order to appropriately treat this population.

**Purpose**

The purpose of this project is to create a workshop that will educate Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists about fibromyalgia syndrome. People who are in the process of being diagnosed with fibromyalgia or who have been diagnosed with fibromyalgia need a therapist who can distinguish between resistant behavior and the waxing and waning symptomology of the syndrome. Once educated, therapists would be able to recognize this medical condition and appropriately treat their therapy clients; they would remove labels such as somatization disorder, factitious disorder or malingering, for this population. In clients not yet diagnosed with fibromyalgia the educated therapist will potentially have the foresight to refer their clients to an appropriate medical doctor for evaluation and treatment. This project would help Marriage and Family Therapy Trainee’s, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists gain greater understanding of the diverse attitudes associated with fibromyalgia as a syndrome and give insight into how that can affect a therapy client.
Significance

As a result of this project, the quality of life for people with fibromyalgia can be improved when Marriage and Family Therapy Trainee’s, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists have a better understanding of their client’s condition, and potential limitations. If the therapist is knowledgeable and prepared with the appropriate treatment options, in advance, for the obstacles that some with fibromyalgia face, their effectiveness for this population of client will improve. In addition, the relationship between the therapist and client diagnosed with fibromyalgia could strengthen as a result of the therapist taking the initiative to understand their client’s subjective reality.

Terminology

The following are a list of terminology used

Factitious disorder – “Factitious disorders are characterized by physical or psychological symptoms that are intentionally produced or feigned in order to assume the sick role…the motivation is a psychological need …as evidence by an absence of external incentives for the behavior” (American Psychiatric Association [APA], 2000, p. 513)

Malingering – Malingering is distinguished from factitious disorder. “In malingering, the individual also produces the symptoms intentionally, but has a goal that is obviously recognizable when the environmental circumstances are known” (APA, 2000, p. 513)

Examples: the production of symptoms to avoid jury duty or going to school.
Somatization disorder- According to the DSM-IV- TR (2000), the criteria for

Somatization disorder includes all of A-D:

A. A history of several physical complaints starting before age 30 that occur over
many years and result in the seeking of treatment “or significant impairment
in social, occupational or other important areas of functioning” (APA, 2000,
p. 490).

B. All of the following; four pain symptoms, two gastrointestinal symptoms, one
sexual symptom, and one pseudoneurological symptom:

1. “…A history of pain related to at least four different sites or functions
(e.g., head, abdomen, back, joints, extremities, chest, rectum, during
menstruation, during sexual intercourse, or during urination)” (APA,
2000, p. 490).

2. Two gastrointestinal symptoms other than pain, for example: bloating,
nausea, diarrhea, and intolerance to different food.

3. “A history of at least one sexual or reproductive symptom other than
pain (e.g., sexual indifference, erectile or ejaculatory dysfunction,
irregular menses, excessive menstrual bleeding, vomiting throughout
pregnancy)” (APA, 2000, p.490).

4. “…A history of at least one symptom or deficit suggesting a
neurological condition not limited to pain” (APA, 2000, p. 490).
C. All of the above cannot be explained by a general medical condition or if they can the complaints and social and occupational limitations are in excess of what is expected.

D. “The symptoms are not intentionally produced or feigned (as in Factitious Disorder or Malingering)” (APA, 2000, p. 490).

Symptom severity (SS) scale score – “The SS scale score is the sum of the severity of the 3 symptoms (fatigue, waking unrefreshed, cognitive symptoms) plus the extent (severity) of somatic symptoms in general. The final score is between 0 and 12 ” (Wolfe et al., 2010, p. 607). For fatigue, waking unrefreshed, and cognitive symptoms, use the following scale “0 = no problem; 1 = slight or mild problems, generally mild or intermittent; 2 = moderate, considerable problems, often present and/or at a moderate level; 3 = severe: pervasive, continuous, life-disturbing problems” (p. 607).

Considering somatic symptoms in general, indicate whether the patient has muscle pain, irritable bowel syndrome, fatigue/tiredness, thinking or remembering problems, muscle weakness, headache, pain/cramps in the abdomen, numbness/tingling, dizziness, insomnia, depression, constipation, pain in the upper abdomen, nausea, nervousness, chest pain, blurred vision, fever, diarrhea, dry mouth, itching, Raynaud’s phenomenon, hives/welts, ringing in the ears, vomiting, heartburn, oral ulcers, loss of/change in taste, seizures, dry eyes, shortness of breath, loss of appetite, rash, sun sensitivity, hearing difficulties, easy bruising, hair loss, frequent urination, painful urination, and bladder spasms (Wolfe et al., 2010, p.607).
Use the following scale to give a score for somatic symptoms: “0 = no symptoms; 1 = few symptoms; 2 = a moderate number of symptoms; and 3 = a great deal of symptoms” (Wolfe et al., 2010, p.607).

Tender points – points on the body where, if painful to the touch with a force of 4 kg (approximately 9 lbs.) in at least 11 of 18, meets the 1990 ACR diagnostic criteria for fibromyalgia syndrome. The locations are as follows: Occiput; low cervical; trapezius; supraspinatus; second rib; lateral epicondyle; gluteal; greater trochanter; and the knee all bilateral totaling 18. (Wolfe et al. 1990, p. 171)

Widespread pain –

Pain is considered widespread when all of the following are present: pain in the left side of the body, pain in the right side of the body, pain above the waist, and pain below the waist. In addition, axial skeletal pain (cervical spine or anterior chest or thoracic spine or low back) must be present. In this definition, shoulder and buttock pain is considered as pain for each involved side “low back” pain is considered lower segment pain (Wolfe et al. 1990, p. 171).

Widespread pain index (WPI) score – To determine a WPI score, note the number of areas in which an individual has pain over the last week. The total number will be between 0 and 19, 1 point is given for each of the following areas: shoulder girdle, left; shoulder girdle, right; upper arm, left; upper arm, right; lower arm, left; lower arm, right; hip (buttock, trochanter), left; hip (buttock, trochanter), right; upper leg, left; upper leg,
right; lower leg, left; lower leg, right; jaw, left; jaw, right; chest; abdomen; upper back; lower back; and neck. (Wolfe et al., 2010, p. 607).

In order to better understand this issue, it is necessary to review the research regarding the definition and attitudes of fibromyalgia syndrome and its affect on those who are given the diagnosis, which will be covered in the following chapter.
Chapter II
Review of Literature

The purpose of this chapter is to first, introduce the reader to the concept of fibromyalgia syndrome and its epidemiology and etiology. The second is to explain the history and genesis of fibromyalgia, as a diagnosis, and highlight the stigma attached to those who carry the diagnosis, by some in the medical community. The third is to introduce some of the psychosocial and psychological factors associated with the syndrome. The forth is to provide examples of the impact the syndrome has on the people who are diagnosed with it, including the concept of an invisible disability. Finally, a look at treatments including how the therapist can treat a client with the diagnosis or who has symptoms of fibromyalgia will be presented.

Fibromyalgia

The word fibromyalgia comes from both ancient Latin and Greek, combining the Latin word for fibrous tissue (fibro) with the Greek words for muscle (myo) and pain (algia) (Yu & McNett, 2006). Fibromyalgia is a syndrome and not a disease (Mitchell, 2011). Mitchell (2011) defines the term disease as a medical condition where there is a particular cause or causes, as well as, signs and symptoms that doctors can recognize. A syndrome is defined as a collection of signs, symptoms, and medical problems that occur together but are not related to one specific, identifiable cause (2011).

According to Velkura and Colburn (2009), fibromyalgia can be found in 3-5% of the general population. Fibromyalgia is more common in women than in men and the
frequency of diagnosis increases progressively with age. It is diagnosed most frequently in middle-aged women however it occurs in children and in as many as 1-2% of adolescents. The researchers report that 15% of patients hospitalized in internal medicine wards have fibromyalgia, 91% of whom were women. They indicate a genetic and environmental factor may be present considering that fibromyalgia patients are more likely to have a relative with the diagnosis as well (2009).

**Etiology**

According to Velkura and Colburn (2009), there are many theories explaining the cause of fibromyalgia, “…including muscle injury, non-refreshing sleep, neurohormonal abnormalities, psychophysiology, and abnormal sensory processing of pain signals” (2009, para. 5). However, they point out that the etiology and pathophysiology of fibromyalgia remains elusive (2009).

Velkura and Colburn (2009) suggest that environmental stress factors such as war, catastrophic events, physical trauma, accidents, illness or emotional stress can trigger fibromyalgia symptoms. They indicate that chronic pain in adulthood correlates to adverse childhood experiences such as poverty, or physical or sexual abuse. They note, “Several retrospective studies suggested that physical trauma may precipitate fibromyalgia” (2009, para. 10). In addition, Fibromyalgia patients who have psychological trauma associated with anxiety related to childhood trauma or sexual abuse appear to have a greater number of tender points (2009).

These researchers believe there are elevated levels of the neurotransmitter Substance P in people with fibromyalgia. Substance P is associated with enhanced pain
perception. Serotonin and baseline cortisol levels are low and there is a blunted adrenal cortical response to Adrenocorticotropic hormone (ACTH). In addition, “Derangement of the hypothalamic-pituitary-adrenal (HPA) axis and the autonomic nervous system along with hyperactivity of the stress response was observed in patients with fibromyalgia” (2009, para.11). The researchers note that this HPA axis activity may be related to trauma experienced in childhood especially if it was physical. Early exposure to chronic stress can permanently affect the HPA axis, which can then lead to fibromyalgia (Velkura & Colburn, 2009).

**Characteristics**

Velkura and Colburn (2009) report that people with fibromyalgia exhibit *Allodynia*, which is when normally non-painful stimuli is painful, and *Hyperalgesia*, which is extreme sensitivity to what is considered painful stimuli. They also indicate that it is common for the symptoms of fibromyalgia to wax and wane. Fatigue is routinely at its worst in the morning and persists throughout the day. Symptoms can be aggravated by cold and humid weather, physical or mental stress and poor sleep. Velkura & Colburn (2009) name some other symptoms people with fibromyalgia may experience including, lightheadedness, fluid retention, post-exertion pain, palpitations, night sweats, dysmenorrhea (pain during menstruation), sexual dysfunction, allergic symptoms, paresthesias (sensation of numbness, tingling, crawling, or burning), mood disturbances (particularly depression and anxiety, and personality disorders), cognitive dysfunction (difficulty with concentration and short–term memory loss), and headaches (both muscular and migraine types) (2009).
In addition, Velkura and Colburn (2009) list the most common regional pain syndromes that coexist with fibromyalgia: Temporomandibular joint disorders (TMJ), myofascial pain syndrome, irritable bowel syndrome, irritable bladder syndrome, interstitial cystitis, restless leg syndrome, and chronic fatigue syndrome (2009).

**History of Diagnosis**

Smythe and Moldofsky (1977) were the first to describe “fibrositis” syndrome in a Bulletin on the Rheumatic Disease published by The Arthritis Foundation. The label was given to a group of patients whose symptoms did not fit the usual disease process or patterns. “…The label has had such historically inconsistent clinical, psychological and pathological implications that about half of rheumatologists rarely make the diagnosis, while the other half believe it makes up an important and challenging fraction of their practice” (p.928). These researchers introduced the symptomatology of (1) chronic aching, (2) exaggerated tender point pain in 12 or more of 14 specific sites, (3) non restorative sleep patterns with morning fatigue and stiffness, and (4) the Electroencephalography (EEG) result of alpha intrusion in non rapid eye movement (REM) sleep as criteria in diagnosing these patients. “These criteria may also help to differentiate ‘fibrositic’ pain from pain which is purely malingering pretense, or neurotically symbolic” (p. 931) Smythe and Moldofsky (1977) made clear “In our opinion, the existence of exaggerated tenderness at anatomically reproducible locations is central to acceptance and recognition of the syndrome” (p. 928). The researchers hoped, with these criteria, to “identify this subset of patients, and direct the therapist away from
purely disease suppressive measures, and away from purely psychologic explanations” (1977, p. 931).

Wolfe et al. (1990) wrote that after the release of the Smythe and Moldofsky (1977) article, there was new interest in the neglected syndrome, and more than 60 research papers were written about fibrositis. In 1990, in association with the American College of Rheumatology (ACR), Wolfe et al. (1990) established the diagnostic criteria for fibromyalgia syndrome, formerly known as fibrositis syndrome. These criteria included (1) a history of widespread pain for at least three months and (2) pain must be present, to the degree of mild or greater, in 11 of 18 tender points when digital palpation is performed with approximately 4 kg (approximately 9 lbs.) of force (1990).

At the time of the 1990 study, Wolfe et al. found sleep disturbance, fatigue, and stiffness to be central symptoms of fibromyalgia, occurring in more than 75% of people with fibromyalgia. In addition, symptoms such as anxiety and irritable bowel syndrome were identified as more common in people with fibromyalgia than in controls, yet they were not added to the diagnostic criteria. There was consensus among the investigators that fibromyalgia often occurs in association with other rheumatic disorders, and it was specified that the presence of a second clinical disorder does not exclude the diagnosis of fibromyalgia (1990).

Mease and Seymour (2008) write that the 1990 ACR criteria was intended to be used for the purpose of research only but was then generalized to be used for diagnostic purposes. They state that “although the tender point examination helps physicians discriminate [fibromyalgia syndrome] FMS as a condition characterized by augmented tenderness, an increased number of tender points is associated with female sex and
‘distress’” (2008, para. 3). In addition, the exclusion of patients with chronic widespread pain but not enough tender points as well as the lack of “clear-cut biomarkers” has lead to skepticism among physicians as well as the frustration of patients (2008).

In the Bulletin of the World Health Organization (WHO), Ehrlich (2003) wrote:

> Although classification criteria were promulgated for study purposes, these have been taken as diagnostic criteria by some and thus seem to validate the diagnosis. Fibromyalgia is, however, an example of a *meme* disorder— an infectious disease not caused by a microcosm but by imitative behavior. Associated symptoms are self reported and thus not subject to verification and other “symptoms” have been imputed, so that the name given to the symptoms depends on the preponderance of associated features reported. No real working definition of fibromyalgia has been formulated, however, so that patients thus diagnosed do not differ materially from others who have widespread chronic pain. This subgroup, however, is more likely to display socially maladaptive traits (p.673).

Twenty years after the 1990 ACR criteria was established, Wolfe et al. (2010) postulated that although the 1990 ACR criteria for the diagnosis of fibromyalgia syndrome remain effective in the diagnosis of fibromyalgia, an alternative diagnostic procedure was needed. First, these researchers stated that the tender point count was rarely performed in the primary care setting where most fibromyalgia diagnoses were being made; many primary care physicians did not know how to perform the tender point examination or refused to do the procedure. The consequence being, a fibromyalgia diagnosis, in practice has often become a symptom-based diagnosis. Second, the 1990 ACR criteria left out what became increasingly known as key fibromyalgia features:
fatigue, cognitive symptoms, and a range of somatic symptoms. These researchers acknowledged “…a number of fibromyalgia experts who believed that tender points obscured important considerations and erroneously linked the disorder to peripheral muscle abnormality” (2010, p.601).

In this study, Wolfe et al. (2010) found that 25% of the diagnosed fibromyalgia patients did not meet the 1990 ACR criteria for fibromyalgia although they were considered to have the syndrome by their physician. The loss of a tender point or a painful region for any reason can mean loss of a diagnosis. They state that fibromyalgia is different than other rheumatic diagnoses like rheumatoid arthritis and systemic lupus erythematosus where patients continue to have their condition although they may not meet the diagnostic criteria because they are not based on symptom severity. Wolfe et al. suggest the symptom severity (SS) scale as a solution to this problem. Once the patient has been diagnosed the SS scale can be used to follow the patients current symptoms (2010).

It is important to note in the creation of the SS scale the researchers omitted mood as a variable although it showed a correlation with the SS scale at 0.725 and with these other components: cognition at 0.625, somatic symptoms at 0.621, waking unrefreshed at 0.619, and fatigue at 0.612 respectively. Wolfe et al. stated that mood was difficult to assess; they could not distinguish if it was a result of having fibromyalgia or a feature of the condition. In addition, “of the binary variables, irritable bowel syndrome, abdominal pain, and headache had variable importance. However, they added no power to correct classification and we did not include them in the diagnostic criteria” (2010, p. 608).
Wolfe et al. (2010), in accordance with the ACR, proposed that as part of the preliminary new diagnostic criteria for the diagnosis of fibromyalgia, the following three conditions must be met (1) Widespread pain index (WPI) $\geq 7$ and SS $\geq 5$ or WPI $3 – 6$ and SS $\geq 9$, (see terminology section) (2) symptoms have to be present and at a similar level for at least 3 months, and (3) the patient does not have a disorder that would otherwise explain the pain.

The preliminary ACR diagnostic criterion offers a shift in the conceptualization of fibromyalgia. Wolfe et al. (2010) suggest the new criteria and SS scale shifts the fibromyalgia definition towards important symptoms: first, the criteria can be satisfied if the WPI score is not high enough but the patient has a high level of symptoms and second, the SS scale affords the appropriate importance to other fibromyalgia symptoms.

It is noteworthy that in this new diagnostic criteria, Wolfe et al. (2010) address those in the medical community who had trouble with the 1990 ACR diagnostic criteria or do not believe in the concept of fibromyalgia, “the criteria and severity scale also provides room for those who are uncomfortable with the fibromyalgia concept, as they can simply report the WPI and SS scale” (p.609). This is evidence, written in the diagnostic criteria, as an attempt to resolve previous problems with physicians who, as previously stated, refused to perform diagnostic tests or to consider the syndrome at all due to their lack of belief in its legitimacy (2010).

Although the criteria for fibromyalgia have been advancing through the decades and the syndrome has been given legitimacy by most in the medical community, there are still physicians who do not believe in its existence. The person with fibromyalgia
symptoms may have a variety of positive or negative experiences when seeing a physician for help.

**Psychosocial Factors**

In a study conducted by Wolfe and Hawley (1998) several psychosocial factors were observed in people diagnosed with fibromyalgia. The first apparent thing was that divorce was more likely in people with fibromyalgia than people with other rheumatic diagnoses. In addition, people with fibromyalgia are 4.32 times more likely than the general population, to have ever been divorced (1998).

Wolfe and Hawley (1998) also examined the diagnoses of a group of patients who had rheumatoid arthritis, osteoarthritis, and fibromyalgia. The patients were classified in groups as “coping”, “stressed” and “dysfunctional”, 51% of the fibromyalgia patients were in the “dysfunctional” cluster. The researchers found that there was increased smoking, body mass index (BMI), divorce and lower income and education levels, in the distressed fibromyalgia patients (1998).

In addition, Wolfe and Hawley (1998) write that there have been a number of studies where evidence of physical and sexual abuse has been evident in the history of patients who are diagnosed with fibromyalgia. An excess of alcoholism has been found within families as well (1998).

**Psychological Factors**

Wolfe and Hawley (1998) assert the lifetime depression rate for fibromyalgia patients to be between 20% and 86%. When compared with other rheumatic patients and
healthy controls, the researchers established that the fibromyalgia patients had consistently higher rates of depression (1998).

Wolfe and Hawley (1998) also indicate anxiety is higher in fibromyalgia patients. Anxiety is not researched as much as depression according to the researchers, however, along with somatization, they discovered anxiety to be higher in fibromyalgia patients. According to the researchers, there is an excess of somatic symptoms of perceived importance in the patient-reported symptoms occurring co-morbidly with other fibromyalgia symptoms (1998). Wolfe et al. (2010) has attempted to incorporate the importance of these somatic complaints into a new diagnostic criterion for the syndrome.

In a blind study examining whether mortality was increased in fibromyalgia patients, Dreyer, Hendall, Danneskiold-Samsoe, Bartels and Bliddal (2010) found the suicide risk was over ten times that of the general population. They reported that none of the patients who had committed suicide had a medical history of depression or other psychiatric illnesses at the time they were diagnosed with fibromyalgia. Suicide was observed in fibromyalgia patients both in the short-term after diagnosis and long-term after they were diagnosed. The suicide risk was elevated at the time of diagnosis and remained elevated after five years. The researchers concluded first, there was a need for depression/risk factors for suicide in patients being diagnosed with fibromyalgia and second, there was further support for the hypothesis that pain comes first and the depression follows it (2010).

The researchers overall findings did not show that a fibromyalgia diagnosis itself predicts an increased risk of death compared with the general population. However, Dreyer et al. (2010) discovered, along with the increase in suicide deaths, that those with
fibromyalgia were more than six times more likely than the general population to die from cirrhosis/biliary tract disease and three times more likely to die from cerebrovascular disease. According to the researchers, this evidence suggests that along with being monitored for suicide risk, those diagnosed with fibromyalgia should also be evaluated for risk factors associated with liver disease and cerebrovascular disease as well (2010).

**Invisible Disability**

Davis (2005) describes severe fibromyalgia as one of several *invisible disabilities* which also includes severe depression, chronic pain, posttraumatic stress disorder (PTSD), chronic fatigue syndrome (CFS), people with seizure disorders, people who are violently allergic to common household chemicals, and those who have sustained a mild traumatic brain injury (MTBI). There are individuals with conditions and illnesses that are life limiting but not easily discernable to others. People with fibromyalgia may appear capable of “normal” functioning to casual acquaintances. The quality of life of those with invisible disabilities may be as adversely affected as those whose disabilities are more obvious to an observer. “There is no reason to believe that the invisibility of a disability itself necessarily lessens its impact or makes the disability less serious” (p. 154). “Though not as easily stigmatized in obvious or familiar ways, persons with invisible disabilities are subject to forms of rejection, humiliation, and social disapproval that are importantly similar” (2005, p.154). It is more difficult for a person with an invisible disability to get assistance or necessary accommodations when he or she is not “seen” as needing help. This includes family and friends who do not understand fibromyalgia or
who may have become overwhelmed by the extra tasks they must take on once their family member is at a decreased functional state (2005).

In addition, Davis (2005) notes that those suffering from an invisible disability like fibromyalgia may have to convince other people that they really are disabled and not seeking special privileges or unfair advantages. They must meet the burden of proof.

Davis (2005) wrote:

They thus face a double bind: either they forgo the assistance or accommodation they need - and thus suffer the consequences of attempting to do things they may not be able to do safely by themselves - or they endure the discomfort of subjecting themselves to strangers’ interrogations (2005, p. 154-155).

**Treatment**

Mease and Seymour (2008) suggest that each fibromyalgia patient’s treatment plan should be tailored to the individual needs of that patient. They found the most effective treatments to consist of both pharmacologic and nonpharmacologic interventions. They suggest the “cornerstone” of treatment should be nonpharmacologic including such interventions as conditioning exercise, family and patient education, and therapy. Clinical trials showed that patient education improved depression, health satisfaction, pain, pain control, and pain behavior (2008, para. 15).

Mease and Seymour (2008) write:

Education is important because many patients have experienced a frustrating diagnosis and treatment path and may have developed a distrust about communication with clinicians. In addition, they may have unrealistic expectation
about the potential benefit of treatment and therefore need an explanation of what
is possible (2008, para. 15).

Fibromyalgia is a syndrome that is managed and not cured (2008).

Mease and Seymour (2008) found that “[Cognitive Behavioral Therapy] CBT has
been explored as a treatment for patients with FMS because it has been used effectively
to manage other chronic pain conditions” (2008, para. 15).

Complimentary and alternative medicines (CAM) are used by many with
fibromyalgia and may be of benefit, however the scientific evidence to support the
therapeutic benefits of CAM therapies is not solid (Mease & Seymour, 2008). According
to The National Fibromyalgia Association (NFA) (n.d.) these alternative therapies
include: acupuncture, chiropractic care, yoga, massage, myofasical release, and herbal
supplements. They also add reducing stress, pacing activities, increasing rest, and
improved nutrition as factors in improving quality of life and minimizing symptoms
(National Fibromyalgia Association [NFA], n.d.). Velkura and Colburn (2009) include
meditation, biofeedback, hypnotherapy, energy therapy, trigger point injections, and tai
chi as alternative treatment options (Velkura & Colburn, 2009).

Mease and Seymour (2008) recommend a multimodal treatment approach that
includes medication, exercise, education, therapy, and CAM.

Mease and Seymour (2008) write:

Ongoing comanagement by both the primary care physician and specialist team
provides optimal avenues for communication with the patient and among
caregivers and for fine-tuning treatment; dealing with medication tolerability
issues; and navigating issues that affect family, social, and work relationships (2008, para. 39)

**Pharmacotherapy**

Traynor, Thiessen and Traynor (2011) performed a meta-analysis on the pharmacologic agents being used in the treatment of fibromyalgia. In the review, they look at the clinical trial results of many off label medications that have been used to treat fibromyalgia with mixed results including opioids, tricyclic antidepressants (TCA), selective serotonin-reuptake inhibitors (SSRI), and gabapentin. They also look at the three medications that were only recently labeled as a treatment for fibromyalgia in the United States, duloxetine – a serotonin and norepinephrine reuptake inhibitor (SNRI), milnacipran (a SNRI), and pregabalin (a ligand), the brand names Cymbalta, Savella, and Lyrica respectively (2011).

According to the findings of Traynor et al. (2011), TCA’s are prescribed at a much lower dose for fibromyalgia treatment than what would be considered the effective dose for the treatment of depression. TCA’s mechanism for improvement for fibromyalgia symptoms is not completely understood however; it is thought that the increase in serotonin and norepinephrine in spinal neurons through TCA’s mechanism of reuptake inhibition creates an analgesic effect, which reduces pain. The most commonly studied TCA in conjunction with fibromyalgia treatment is amitriptyline. Amitriptyline (brand name Elavil) at a dose of 25mg (100-150mg for depression) was shown to produce statistically significant benefits for the fibromyalgia symptoms of pain, sleep disturbances, and fatigue at 6 to 8 weeks, and then at 12 weeks results diminished and were no longer significant. At a dose of 50 mg there was no therapeutic benefit for which
they could not explain. The most common adverse effects were weight gain, dry mouth, gastrointestinal symptoms, and somnolence (2011).

Traynor et al. (2011) located a small study comparing amitriptyline, nortriptyline, and placebo. The TCA nortriptyline (brand names Pamelor or Aventyl) is the active metabolite of amitriptyline and has a lower occurrence of adverse effects. There was no significant improvement in the nortriptyline and amitriptyline groups Fibromyalgia Impact Questionnaire (FIQ) scores when compared to placebo (2011).

Traynor et al. (2011) report that the TCA imipramine (brand name Tofranil) was studied in 20 people in Israel. The results showed that two people improved, eight discontinued within the first month for lack of effectiveness, and 35% reported adverse effects such as loss of balance, nervousness, and dry mouth (2011).

Traynor et al. (2011) looked at cyclobenzaprine (brand names Amrix, fexmid, and Flexeril), which is structurally similar to TCA’s yet, are typically used as muscle relaxers. In an analysis of several studies of the use of cyclobenzaprine for fibromyalgia treatment at 10 or 30 mg, some benefit was found. Over 12 weeks there was improvement in sleep and improvement in pain early on, however there were no improvements in tender points or fatigue. There was a high drop out rate and 85% reported at least one adverse effect (2011).

According to the Traynor et al. (2011) research, it was hypothesized that “altering serotonin levels with selective serotonin-reuptake inhibitors (SSRIs) might be superior to alteration of norepinephrine levels in improving some symptoms of fibromyalgia” (2011, p. 1311). “In general, SSRIs are better tolerated than TCAs because they have fewer anticholinergic adverse effects; however, they have been less effective than TCAs for the
treatment of the pain of fibromyalgia” (2011, p. 1311). Fluoxetine, Paroxetine, and Citalopram have been studied for the treatment of fibromyalgia (2011).

Traynor et al. (2011) looked at a 1994 study comparing 20 mg of fluoxetine (brand name Prozac) daily with placebo. There was no significant difference between the fluoxetine and placebo groups in depression, anxiety, pain, fatigue, sleep quality, or tender point score or count at three weeks, yet there was a decrease in self rated anxiety. Using the Beck Depression Inventory (BDI) and the Arthritis Impact Measurement Scale (AIMS) the fluoxetine group had significant improvement from baseline to 6 weeks for depression. In another fluoxetine study, this time using patients with fibromyalgia who did not have active depression, the fluoxetine group’s FIQ scores showed significance for pain, depression and fatigue. This study had a high unexplained, drop out rate of 62% (2011).

Traynor et al. (2011) also looked at a crossover study that involved a combination of fluoxetine (20mg) and amitriptyline (25mg) compared to placebo. Thirty-one patients started the study and 12 dropped out for adverse reactions. Using the FIQ and Visual Analogue Scale (VAS), the combination of fluoxetine and amitriptyline significantly improved global well-being, sleep disturbances, and pain. There was more improvement in these symptoms using the medications together than each medication on their own (2011).

Traynor et al. (2011) looked at a study done on paroxetine (brand name Paxil), with a dosage between 12.5-62.5 mg with a mean dosage of 39.2 mg, versus placebo for the treatment of fibromyalgia treatment. The study began with 116 subjects and ended with 86 due to drop out. The FIQ scores showed paroxetine improved “days felt good”,

23
anxiety, and fatigue however there was no improvement for any other subscale score including pain or depression. The most common adverse effects reported were headaches, dry mouth, drowsiness, ejaculatory problems, and impotence (2011).

Citalopram (brand name Celexa) was compared to placebo for fibromyalgia treatment in two studies (8 and 16 week trials). With a total of 82 subjects, there was no improvement in well-being or pain using citalopram for fibromyalgia treatment in either trial (Traynor, Thiessen, & Traynor, 2011).

Traynor et al. (2011) examined the use of serotonin-and norepinephrine-reuptake inhibitors (SNRIs) for their use in the treatment of fibromyalgia syndrome. SNRIs are thought to be an appropriate fibromyalgia treatment choice because they potentially have analgesic properties that “are thought to arise from effects on descending inhibitory pathways in the spinal cord” (2001, p. 1312). SNRIs may also be helpful in treating anxiety and depression that often accompanies fibromyalgia pain. The SNRIs venlafaxine, duloxetine and milnacipran have been studied in relation to fibromyalgia in clinical trials (2011).

Traynor et al. (2011) looked at two small open label trials of venlafaxine (brand name Effexor) for the treatment of fibromyalgia. The first study was an 8-week trial with 15 subjects using a dosage range of 37.5-375 mg per day. The second study was a 12-week, 20 subject trial with a dosage range of 75 mg daily. Using the VAS and McGill Pain Questionnaire there was improvement for pain however, because of the small trials venlafaxine has not been recommended as a treatment for fibromyalgia at the current time (2011).
Traynor et al. (2011) investigated five trials of duloxetine (brand name Cymbalta) for the treatment of fibromyalgia. At a dose of 60 and 120 mg duloxetine is efficacious for pain and other symptoms, there is no evidence of efficacy at 20 mg. In four of the five trials, duloxetine showed significantly better results on the Patient Global Impression of Change (PGIC) and improvement in pain intensity scores on the Brief Pain Inventory (BPI). The Clinician Global Impression of Change (CGI-C) showed improvement in quality of life in all five trials. There was no improvement for fatigue or sleep, yet the degree to which sleep was interrupted by pain was improved. Mental fatigue showed improvement in the two studies that measured it. Two of the trials measured for anxiety and depression with no significance. “Additional analysis in these trials indicated that 61-87% of the observed improvement in pain scores was attributable to duloxetine’s direct effects on pain, with the remainder attributable to its effects on depression and anxiety” (2011, p.1313). Duloxetine is generally tolerated well with the patients at 60 mg twice a day having a discontinuation rate significantly higher than the 60 mg a day group. Adverse effects reported were tremor, hyperhidrosis, decreased appetite, somnolence, constipation, nausea, and dry mouth (2011).

Traynor et al. (2011) evaluated three high quality studies done on milnacipran (brand name Savella) in the treatment of fibromyalgia. All three trials found milnacipran to be effective for pain relief and improvement with fatigue. In two of the trials the VAS pain score, PGIC ratings, and the Medical Outcomes Study Short Form-36 (SF-36) were used to evaluate eight quality-of-life measures with a finding of milnacipran revealing global improvement. The third trial showed twice daily dosing to be more effective than once daily dosing. In addition, the PGIC scores showed significance but not the FIQ
scores. Two of the three trials showed improvement in cognition. Milnacipran had no effect on sleep. It is generally well tolerated, however adverse effects include a mild increase in blood pressure and resting heart rate, sweating, flushing, nausea and headaches (2011).

Traynor et al. (2011) found only one opioid related study for fibromyalgia treatment. The study was done using tramadol (brand names Rybix, Ryzolt, and Ultram) “whose mechanism of action includes not only agonist activity at the µ-opioid receptor but also inhibition of the reuptake of serotonin and norepinephrine” (2011, p. 1313). In a meta-analysis of studies of adverse effects and effectiveness of opioids for chronic pain (not related to cancer), 7% of the 6019 subjects had fibromyalgia. They concluded that opioids were effective in improving functionality and pain relief. Strong opioids such as morphine and oxycodone were found to be more effective than TCAs and nonsteroidal anti-inflammatory medications. “However, no trials have directly compared the effects of opioids with those of any other medication class in patients with fibromyalgia” (2011, p. 1313). There is controversy concerning the use of opioids in the treatment of fibromyalgia, some for the lack of evidence of its effectiveness. Traynor et al. (2011) discovered that “Harris et al. found that there is a deficit in opioid-mediated descending antinociceptive activity in patients with fibromyalgia as a result of decreased µ-opioid receptor availability due to increased concentrations of endogenous opioids within the cerebrospinal fluid” (2011, p. 1313). Traynor et al. (2011) say that others discourage opioid use because of concerns with dependence and overprescribing (2011).
Traynor et al. (2011) discovered that ligands such as pregabalin and gabapentin have been studied for use as a fibromyalgia treatment because of the evidence that the etiology of fibromyalgia may involve an excess of excitatory neurotransmitters. Traynor et al. (2011) write:

These drugs act on nerves at the α2δ subunit of voltage-gated calcium channels. In the presence of pregabalin or gabapentin, the calcium channels admit less calcium, an action that decreases the downstream release of excitatory neurotransmitters such as substance P, glutamate, and norepinephrine (2011, p. 1313).

Traynor et al. (2011) looked at several studies performed using pregabalin (brand name Lyrica) for use in the treatment of fibromyalgia. Pain was significantly reduced, in several studies, in those who took pregabalin at the 300, 450, and 600 mg doses. Studies that evaluated the effects pregabalin had on fatigue produced conflicting results yet a previous meta-analysis revealed it had modest effects in diminishing fatigue. Sleep was improved with pregabalin however according to some Medical Outcome Study-Sleep (MOS-Sleep) results, it also caused daytime somnolence. There were no study measurements for cognitive function tested. In the meta-analysis, anxiety was significantly reduced however, in individual trials anxiety showed no significance. Quality of life was shown to have modest improvement in some areas and PGIC scores improved. The main adverse effects reported, with higher doses producing more adverse effects, are weight gain, dizziness, somnolence, and headache (2011).

Traynor et al. (2011) found one study of gabapentin (brand name Neurontin) for the treatment of fibromyalgia. With dosages at 1200-2400 mg per day, gabapentin was
effective in the reduction of pain. There were improvements in the subjects MOS-Sleep, PGIC, and FIQ scores. Adverse effects include weight gain, lightheadedness, somnolence, and dizziness (2011).

Traynor et al. (2011) investigated other drugs that have been studied for the treatment of fibromyalgia but are not common in clinical practice. Ondansetron (brand name Zofran) is a 5-HT3-receptor antagonist, which may have analgesic effects. Ondansetron was studied because some fibromyalgia symptoms may be related to a deficiency in serotonin. “Ondansetron treatment resulted in significant decreases in VAS scores for pain, tender-point scores, and average pain threshold” (2011, p.1314). Fifty-five percent of the subjects were “responders” to ondansetron with the most common adverse reactions being dry mouth and constipation (2011).

Traynor et al. (2011) looked at a pilot study done with 10 women taking 4.5 mg of naltrexone (brand names Depade and ReVia) daily for four weeks. “The investigators hypothesized that naltrexone could reduce proinflammatory cytokines and decrease thermal Hyperalgesia through a mechanism not related to its opioid-antagonist effects” (2011, p.1315). Using the VAS six of the ten subjects had a 30% reduction in fibromyalgia symptom severity with adverse effects being reported to be of “very low incidence” (2011).

Traynor et al. (2011) looked at studies done on the use of atypical antipsychotics for use in fibromyalgia treatment. Olanzapine (brand name Zyprexa), quetiapine (brand name Seroquel), and ziprasidone (brand name Geodon) were studied. The olanzapine studies reported a significant decrease in pain however all reported a high frequency of somnolence and weight gain. A 12-week study was done with quetiapine using 35
subjects with a starting dose of 25 mg adjusting to 200 mg per day according to tolerance. With a mean dose of 69.5 mg daily, significant improvement in FIQ scores in measures of fatigue, stiffness, anxiety, depression, and “days felt good” were found at 4 and 12 weeks (but not 8 weeks). There was no significance in pain reduction. Adverse effects include headache, dizziness, nervousness, somnolence, and asthenia (lack of muscle strength or weakness) (2011). An efficacy trial was done to evaluate the efficacy of the final atypical antipsychotic ziprasidone for use with fibromyalgia patients. A range of 20-80 mg (mean of 40 mg) was used on 32 subjects (7 withdrew and their data was not used). Using CGI-C scores, 32% were considered to have responded to the medication. There was no significant change in their FIQ or PSQI scores but based on self-evaluation questionnaire the investigators found anxiety, sadness, and morning stiffness significantly improved. The most common adverse effects included headache, dizziness, restlessness, insomnia, and tremor. Although each atypical antipsychotic is slightly different in their affinity to specific neurotransmitters, all trials had some patients that experienced improvement in overall functioning (2011).

Traynor et al. (2011) looked at studies of dopamine3-receptor (D3) agonists in the treatment of fibromyalgia. “Dopamine3-receptor agonists are thought to decrease the adrenergic arousal that occurs in patients with fibromyalgia, thereby decreasing symptoms such as disordered sleep” (2011, p.1315). A 14-week trial with 60 subjects, using a starting dosage range of 0.25 to 4.5 mg daily of pramipexole dihydrochloride was completed with results of 42% having a reduction in pain according to the VAS. “A trial of extended-release pramipexole versus placebo for fibromyalgia was terminated in 2009 due to a business decision by the drug’s manufacturer (personal communication, Barbara
Traynor et al. (2011) point out that “fibromyalgia management is complicated by the relative subjectivity of diagnostic criteria; patient-specific factors, such as socioeconomic status, functional ability, and comorbidities; and the relatively small amount of definitive evidence on which to base treatment decisions” (2011, p.1316). In addition, “like most of the available evidence on the pharmacotherapy of fibromyalgia, meta-analytical methods do not take into consideration important factors such as patients preference, medication costs, and the risks of serious adverse effects” (2011, p.1316).

In addition, Traynor et al. (2011) found throughout their meta-analysis that there was a notably high drop out rate in the studies they looked at, many of which gave no explanation, the ones that did were for lack of effect and adverse side effects. It is also noteworthy that Traynor et al. (2011) included in their review, although not their focus, the nonpharmacologic intervention of aerobic exercise and water therapy as a beneficial treatment for fibromyalgia syndrome. They note the importance for the fibromyalgia patient and their practitioners to proceed with caution when prescribing exercise “as patients with fibromyalgia often note that flare-ups are precipitated by overexertion” (2011, p. 1317). They suggest a “combination of appropriate pharmacotherapy and gradually increasing exercise treatment. Water therapy and gradually increasing exercise programs may be effective ways of achieving regular habits” (2011, p. 1317).

In Summary, Traynor et al. (2011) establish:

- There are currently three FDA approved pharmacotherapy treatments for fibromyalgia: the SNRI duloxetine (Cymbalta), the SNRI milnacipran (Savella),
and the ligand pregabalin (Lyrica). The most common adverse effects reported for these drugs are: duloxetine (Cymbalta) – tremor, hyperhidrosis, decreased appetite, somnolence, constipation, nausea, and dry mouth; milnacipran (Savella) – mild increase in blood pressure and resting heart rate, sweating, flushing, nausea, and headache; pregabalin (Lyrica) – weight gain, dizziness, somnolence, and headache.

- Several off label medications have been studied and used for the treatment of fibromyalgia such as: TCA’s, SSRI’s, SNRI’s, opioids, ligands, atypical antipsychotics, dopamine agonists, and HT3 receptor agonists.

- Although there is some evidence for reduction of symptoms for most of the drugs presented, there is a pattern of high patient drop out rates, that if reported, were due to lack of improvement or adverse reactions (2011).

**Bowen Family System Theory**

Murray, Daniels, and Murray (2006) are the first to establish empirical evidence that the Bowen family system theory (BFST) can be used as a framework for understanding fibromyalgia syndrome. The researchers point out that although efforts have been made to establish the etiology of fibromyalgia, the impact that family relationships and perceived stress have on the severity and development of fibromyalgia syndrome has not been investigated.

Murray et al. (2006) highlight the main points of BFST, which they find support the use of BFST with fibromyalgia patients and their families. The role that anxiety plays in the development of disease is significant for the understanding of BFST. The BFST system designates eight interconnecting concepts related to the concept of chronic
anxiety. (1) Differentiation of self – the separation of the individuals intellectual and emotional functioning, the more distinct the better able the individuals “ability to remain a self in the pressure to conform to a group (Bowen, 1985)” (2006, p. 148). (2) Triangles – this emotional system is “observed when ‘a two-person emotional system is unstable in that it forms itself into a three-person system or triangle under stress’ (Bowen, 1985, p. 478)” (2006, p.148). (3) Nuclear family emotional process – the process within the family through which symptoms develop. (4) Family projection process – the mechanism by which symptoms such as anxiety are passed between members of the nuclear family. (5) Multigenerational transmission process – the process of repeating relational patterns from one generation to another passing on anxiety from one generation to another. (6) Sibling position – “the influence of birth order on individual functioning” (2006, p. 148). (7) Emotional cutoff – “reactive physical distance or emotional withdrawal across generations as a means to manage stress (Kerr & Bowen, 1988)” (2006, p.148). (8) Societal emotional process – “the emotional processes that occur on a large-scale societal level” (2006, p.148). They also consider “emotional reactivity (instinctual, automatic responses to a real or imagined threat) and I-position (an individual’s ability to determine one’s own behaviors, thoughts, and decisions without imposing on the rights of others; Titelman, 1998)” (2006, p.148-149) to be important theoretical constructs to consider (2006).

The researchers assessed whether there was a relationship between perceived stress, the level of differentiation, the level of emotional cut off, and symptom severity. In addition, they examined whether the relationship between perceived stress and
fibromyalgia symptom severity is moderated by their differentiation of self, their level of emotional cut off, their emotional reactivity, or their level of I-position. They found a significant correlation between all the variables and symptom severity; perceived stress, level of emotional cutoff, and level of differentiation. They discovered that as perceived stress increased so did the level of symptom severity. They also found that each variable weakly moderated the relationship between perceived stress and the severity of symptoms, however none contributed a large proportion of variance in symptom severity. They made the following three conclusions: those who exhibited higher levels of perceived stress also exhibited higher levels of symptom severity, those who reported higher levels of differentiation of self experienced less intense fibromyalgia symptoms, and those who had more emotional cutoffs had more severe fibromyalgia symptoms (Murray et al., 2006).

Murray et al. (2006) present the following implications for clinical practice when working with someone with fibromyalgia, the use of instruments such as the Differentiation of Self Inventory-Revised (DSI-R) can be used to identify aspects of family functioning that are problematic such as emotional cutoffs, fusion and emotional reactivity. The clinician should also use family histories, genograms and timelines as well as their professional training to provide the finest care to the client with fibromyalgia. It is the researchers hope that “clinicians consider that health and disease do not occur in isolation but are influenced by multiple factors that include the quality of the family relationships” (2006, p. 157).
Emotional Exposure-based Treatment

Lumley et al. (2008) conducted a study to determine the effectiveness of an emotional exposure-based treatment of traumatic stress for people with fibromyalgia. These researchers have found that many with fibromyalgia have experienced “serious psychological trauma or conflict” (p. 166). They point out that “childhood or adult victimization is common” (p.166) in people with fibromyalgia with over half having “post-traumatic stress disorder (PTSD) or subclinical PTSD (Cohen et al., 2002)” (p. 166). In addition, “patients with FMS [fibromyalgia syndrome] respond to interpersonal conflict with increased pain (Davis, Zautra, & Reich, 2001)” (Lumley et al., 2008, p. 166). Lumley et al. (2008) postulate:

Trauma likely creates difficulties in emotional regulation, such as emotional suppression and avoidance, as well as relationships, such as balancing trust and autonomy. These emotional and interpersonal problems likely contribute to FMS onset or severity in many patients, and may be key reasons that treatments often fail (2008, p.166).

Lumley et al. (2008) state that the “standard cognitive behavioral approaches to pain management (e.g., relaxation, distraction, cognitive reappraisal, problem solving), usually bypass the trauma and avoid or minimize negative emotions to reduce the affective arousal that contributes to pain” (p. 166). However, they have found that the “empirical research on emotional regulation, emotional processing, experiential avoidance, and emotional approach coping” (p. 166) have suggested “avoiding negative emotions is often problematic” (2008, p.166). Lumley et al. (2008) write:
Exposure and emotional processing treatments for PTSD and other anxiety disorders demonstrate the adaptive value of accessing, experiencing, and expressing such emotions (Foa & Kozak, 1986), which informs action tendencies, allows the assimilation of cognitions and emotions, and facilitates stress resolution (2008, p. 166).

While the authors point out the benefits of exposure and emotional processing treatments, they underline that “pain management literature, typically advocates emotional avoidance techniques” (Lumley et al., 2008, p.166). They stress that a “key limitation” for fibromyalgia treatment as well as other chronic pain conditions is the “failure to directly address trauma and subsequent emotional and relational difficulties found in a substantial subset of patients” (2008, p.166).

Lumley et al. (2008) developed an intervention, which is influenced by emotional processing theory for anxiety disorders and integrates written emotional disclosure, distinction between primary and secondary emotions, and “‘affect phobia’ (McCullough et al., 2003), which translates psychodynamic formulations into the parsimonious perspective that emotional experience is fundamentally what is avoided and encourages creative, ‘dosed’ (hierarchically presented) experiential exercises to engage avoided affects” (p.166). In addition, the therapeutic relationship is “a powerful corrective emotional experience when patients try new relational behaviors that they typically avoid, particularly metacommunication” (2008, p.166).

The goal for the Lumley et al. (2008) intervention is to identify participants’ “avoided experiences or stimuli, and then engage the patients in various exposure exercises to these stimuli, so that emotional processing occurs, relearning takes place,
trauma is resolved, and physical symptoms improve” (p.167). These traumas, various in nature, such as abuse, violence, rejection, manipulation, loss, secrecy, etc., “usually involve significant others, extend back to childhood” (p.167), and frequently recur over the years. They postulate “that there is continuity across stressors and generalization of avoided emotions” (p. 167) meaning there is a common theme to the “affects that are avoided and the cognitions that support these affects” (p.167). They note that because people will avoid stimuli that produce a similar affective experience, targeting the most influential trauma is not necessary, “one can target various stimuli, which will elicit the avoided affect and lead to learning” (p.167). The intervention was guided by a set of principles that “tailored to each patient’s unique configuration of avoided experiences, as well as patients openness to various exposure techniques” (2008, p. 167).

The treatment included three major components detecting avoidance, implementing exposure, and negotiating process. Detecting avoidance – In the first few sessions, the primary task “is to identify avoided experiences, including traumatic memories, specific emotions and their expression, interpersonal actions, ideas or images, locations, physical stimuli, and physical sensations (including pain)” (Lumley et al., 2008, p. 167). “In the spirit of joint exploration and curiosity rather than certainty” (p. 167) the therapist acts as an “‘avoidance detective,’ directly inquiring about avoided stimuli” (p. 167), “actively searching for signs of avoidance, including the patient’s behavior with the therapist” (p. 167), the “stimuli that evoke anxiety are targeted for exposure” (Lumley et al., 2008, p.167).

Implementing exposure – Different strategies are used to help patients confront stimuli. There are many techniques but the goal is to reverse avoidance.
Lumley et al. (2008) list:

…From generally less to more intense, these are written emotional disclosure, secrete sharing, imaginal exposure, experiential techniques (empty chair work and two-chair dialog), assertiveness training (including modeling, role-playing, and cotherapist participation), metacommunication with the therapist, in vivo exposure, and communication with significant others in session (2008, p. 167-169).

Homework is also given weekly (Lumley et al. 2008).

Negotiating process – Lumley et al. write:

There is a substantial focus on the relationship between therapist and patient, both as a method to maintain or repair the alliance as well as a vehicle for experimenting with avoided interpersonal behaviors. The therapist needs to monitor the alliance quality, which often is strained as the therapist encourages the patient to confront threatening experiences. The relationship between therapist and patient needs to be discussed openly. To facilitate this, metacommunication is introduced and practiced in the first session, and revisited in every session, typically by negotiating the process – what stimuli are avoided, what exposure techniques to use, how intense to make them, whether change is occurring, and how the patient is feeling about the therapist. Metacommunication also is an interpersonal affect regulation strategy that is often very novel for patients – directly sharing their wishes and frustrations to – and about – an authority (the therapist) (2008, p. 169).
Lumley et al. (2008) pilot tested their treatment on ten women with intractable fibromyalgia syndrome and trauma histories. The subjects had between ten and fifteen one-hour sessions, all ten remained in treatment until completion. They used the Impact of Event Scale – Revised (IES-R) to evaluate “three manifestations of unresolved stress: avoidance, intrusions and hyperarousal” (p. 169). They used the Fibromyalgia Impact Questionnaire – Revised (FIQ; Bennett, 2005) (p.169) to assess the previous weeks fibromyalgia symptoms. The Arthritis Impact Measurement Scales – 2 (AIMS-2; Meenan, Mason, Anderson, Guccione, & Kazis, 1992) (p. 169) was used to “assess limitations in the performance of various behaviors of daily activity during the last month” (2008, p. 169). “The McGill Pain Questionnaire (Melzack, 1975) presents sets of pain adjectives and the values of the highest selected adjectives in each set are summed to yield the Pain Rating Index (PRI)” (2008, p. 169). Psychological symptoms and an overall Global Severity Index (GSI) are provided by the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) (p. 169), and the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) (p. 169) measures the participants’ perception of life satisfaction. At the end of treatment, a decrease in all measures, except life satisfaction, indicates improvement for the subjects (Lumley et al., 2008).

Concerning unresolved stress symptoms (IES-R), a moderate to large effect reduction (0.70) was shown indicating significance. Similarly, the fibromyalgia symptom status (FIQ) also showed large effects (0.74), which the researchers called marginally significant. Results for the BSI – GSI “with respect to specific domains of health and functioning, measures of emotional distress and life satisfaction also had moderate to large effect sizes (ES = 0.79 and 0.77 that were marginally or fully significant)” (Lumley
et al., 2008, p. 170). Disability and pain had small to moderate effects, 0.42 and 0.36 respectively; disability was marginally significant (Lumley et al., 2008).

When Lumley et al (2008) looked at the individual participant outcomes they used the reliable change index (RCI) to “indicate how much change occurred while accounting for measurement error across time” (p. 170). Using conservative cut-offs: 1.96 (p < .05) and an RCI of at least 0.50 to represent a moderate effect, they found that on the IES-R three participants showed large effects (RCI > 1.96); seven total showed a minimum of moderate effects (RCI > 0.50); and one had a score just under the minimum 0.50 with a 0.49. For the FIQ, eight participants had a minimum of moderate effects with four having large effects. Substantial improvements were found on the emotional distress measure; there were eight participants with at least moderate effects, two of which had large effects. There were lower rates for pain and disability. For disability six had a minimum of moderate improvement with three having large gains. However, for pain, four had a minimum of moderate improvement with only one having a large gain. Concerning life satisfaction half the participants had a large effect while the other half showed no effect. Taking into consideration exit interviews, self-reports, and therapists impressions, the overall conclusion for the ten participants was “two patients made substantial improvement, four made moderate and meaningful gains, two showed modest benefits, and two did not benefit at all” (Lumley et al., 2008, p. 170).

At three months post treatment, the participants maintained moderate to large effect scores (between .36 and .79 SD from pretreatment scores), this is noteworthy according to Lumley et al. (2008) considering the short treatment time (10 – 15 sessions) and with participants “with substantial pain, disability, and emotional distress for many
years, which would not be expected to resolve on its own over a few months” (p. 170).

The researchers note that stress symptoms, emotional distress, and life satisfaction improved the most with less improvement with pain and disability. They suggest that, with this treatment stress symptoms are the target and less so is pain and disability. “A provocative possibility is that patients whose post-traumatic stress improves (i.e., better emotional regulation and interpersonal relationships) may be more amenable to and successful with a subsequent course of cognitive-behavior pain management training or rehabilitation” (2008, p. 170).

Lumley et al. (2008) point out that their small sample size, lack of a control group, and the reliance on self-report measures is not sufficient at this time to conclude treatment efficacy. However, their “hope that further development and testing will make available a useful intervention for those patients who currently are not benefiting from cognitive-behavioral treatments such as pain coping skills training, or from multidisciplinary rehabilitation including exercise” (Lumley et al., 2008, p. 171).

**Cognitive Behavioral Therapy**

Jensen et al. (2012) used functional magnetic resonance imaging (fMRI) in a 12-week study of 43 female fibromyalgia patients to validate the role of CBT plays in increased pain-evoked activation in the prefrontal cortex. The researchers used the Acceptance and Commitment Therapy (ACT) form of CBT postulating it as the most effective way to work with this population (2012).

Jensen et al. (2012) write:

Central to CBT-based treatments is the identification of maladaptive behavior patterns characterized by avoidance of, for example, pain and distress. Over time,
such avoidance strategies tend to increase disability without a corresponding
decrease in symptoms. To improve functioning and quality of life, avoidance
behaviors are typically targeted using exposure-oriented interventions.

Acceptance and Commitment Therapy (ACT) is developed within the cognitive-
behavioral treatment approach, and has empirical support for both adult and
pediatric chronic pain. ACT explicitly aims at improving functioning and quality
of life by teaching patients to act more effectively in alignment with personal
values and long-term goals, also in the presence of interfering pain and distress
(i.e. psychological flexibility). Acceptance strategies are promoted to help patients
experience negative thoughts, emotions, and bodily sensations in a more open
way to reduce maladaptive reactions to pain, such as worrying and avoidance
(2012, p. 1495-6).

Jensen et al. (2012) state:

Our brain data demonstrate increased pain-evoked activation of the prefrontal
cortex in response to CBT, combined with increased prefrontal-thalamic
functional connectivity…the thalamus is a critical relay site for pain signals, and
decreased thalamic activity has repeatedly been found in FM and other chronic
pain conditions (p. 1501).

Jensen et al. (2012) admit, “CBT does not directly lead to pain inhibition, but uses
the PFC [prefrontal cortex] to reappraise the experience of pain and redirect attention to
other goals” (p. 1502). In essence CBT revises “the brain’s processing of pain through an
altered cerebral loop between pain signals, emotions, and cognitions; leading to executive
cognitive functions” (p.1502). Rather than focusing on alleviating symptoms, ACT
encourages acceptance of the distress and pain that cannot be directly decreased. In addition, anxiety was reduced through this process (2012).

The preceding review of literature presented the description of fibromyalgia syndrome, as well as the characteristics of the syndrome and its population and prevalence. In addition, the history of the medical diagnosis, insight into some of the psychosocial and psychological issues, as well as some treatment considerations were presented.
Chapter III

Project Audience and Implementation Factors

As presented in the previous chapters, research has shown that people with fibromyalgia have significantly higher rates of depression and alarmingly high rates of completed suicides. Research has also shown doubt within the medical community that the syndrome even exists, the lack of consistency in diagnosis and the waxing and waning of symptoms of an invisible disability are contributing factors to the negative stigma some with fibromyalgia face. It is imperative that a therapists working with this population be aware of the many challenging variables these client’s face in order to effectively treat their clients. This chapter will address a proposed one-day, 6-hour workshop to educate Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and Licensed Psychologists about fibromyalgia syndrome. The next section contains information on the intended population of the workshop, workshop facilitator qualifications as well as the environment in which the workshop will be held. The chapter will conclude with a detailed outline of the workshop schedule.

Development of Project

This project was developed as a result of continuous findings in the research that people with fibromyalgia often lack appropriate support systems and that a Marriage and Family Therapists or Psychologists may be the difference between completed suicide and management of their physical symptoms and depression. The combination of the
disturbing fibromyalgia and suicide research found by Dreyer, Hendall, Danneskiold-Samsoe, Bartels and Bliddal (2010) and the author’s personal experience with a Marriage and Family Therapist who was knowledgeable about fibromyalgia when the author found it necessary, was the inspiration for this workshop. The overall intent of the workshop is to effectively support and treat those who are already diagnosed with fibromyalgia syndrome and to help Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and Licensed Psychologists recognize a cluster of symptoms that may need to be referred to a doctor in clients who are not diagnosed yet; the therapy room is the place many unknowingly put all of these symptoms together.

**Intended Audience**

The workshop is intended for Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists. There are no restrictions concerning age race or gender. Due to limitations of the author; fluency of the English language is required. Due to the nature of the topics being discussed, those with a history or sensitivity to discussions of sexual abuse or suicide should use caution. The workshop will be held throughout Los Angeles and Ventura County in Clinic settings, graduate school settings or in the private sector.

**Personal Qualifications**

Workshop facilitators are required to have knowledge of and experience working with clients with fibromyalgia syndrome. They will be a Marriage and Family Therapy
intern, licensed Marriage and Family Therapist or licensed Psychologist. If extensive knowledge and experience are evident some Marriage and Family Trainee’s will be appropriate. At this time proficiency in the English language is required.

**Environment and Equipment**

The workshop will take place in an easily accessible private location with limited distractions. A clinic conference room would be ideal. The workshop will take place during the day with a break for lunch so the location will be accessible to eating establishments or other arrangements will be made in advance.

The presentation room will need to be equipped with a projection system or monitor that is compatible with displaying a Power Point presentation. This display would need to be large enough for all attendees to see clearly. All participants will be provided with a copy of the Power Point presentation, a writing utensil, additional notepaper and a bottle of water. The room would have to have appropriate seating and tables for the participant’s comfort and note taking. The room will also need a chair for the facilitator.

**Project Outline**

9:00 a.m.  Sign in and meet and greet

9:15 a.m.  Introduction of facilitator

9:30 a.m.  What is Fibromyalgia? Etiology and Characteristics

10:00 a.m. History of Medical diagnosis

11:00 a.m. 10 minute break
11:10 a.m. Psychosocial Factors
11:25 a.m. Psychological Factors
11:55 a.m. Invisible Disability
12:15 p.m. 1 hour lunch break
1:15 p.m. Treatments (general)
1:30 p.m. Pharmacotherapy
2:15 p.m. 10 minute break
2:25 p.m. Bowen Family System Theory (BFST)
2:45 p.m. Emotional Exposure-based Treatment
3:15 p.m. Cognitive Behavioral Therapy (CBT)
3:45 p.m. Questions
4:00 p.m. End workshop
Chapter IV

Conclusion

The purpose of this chapter is to summarize the preceding chapters, provide the author’s thoughts concerning the project, and provide suggestions for future work in the area of understanding clients with fibromyalgia syndrome.

Summary

The purpose of this project was to create a workshop that will educate Marriage and Family Therapy Trainees, Marriage and Family Therapy Interns, Licensed Marriage and Family Therapists and licensed Psychologists about fibromyalgia syndrome. Once educated, therapists will be able to recognize this medical condition and appropriately treat their therapy clients; they would dismiss labels such as somatization disorder, factitious disorder or malingering, for this population. In addition, they will be aware of and can assess for the high rates of depression and suicide risk associated with the diagnosis. In clients not yet diagnosed with fibromyalgia the educated therapist will potentially have the foresight to refer their clients to an appropriate medical doctor for evaluation and treatment. If the therapist is knowledgeable and prepared with the appropriate treatment options, in advance, for the obstacles that some with fibromyalgia face, their effectiveness for this population of client will improve. In addition, the relationship between the therapist and client diagnosed with fibromyalgia could strengthen as a result of the therapist taking the initiative to understand their client’s subjective reality.
Discussion

Similar to rheumatoid arthritis, in the future there may be a definitive diagnostic test for a physiological foundation for fibromyalgia, making it a disease and not a syndrome. In the mean time, what seems to be clear is the connection between the stress triggered by maladaptive relationships, somatic and emotional stress, and even the weather with the flare-ups of fibromyalgia symptoms. In addition, the increase in depression and suicide rates are a clear indicator of the need for a therapist’s role in a fibromyalgia patient’s treatment plan, regardless of any consensus to the syndromes etiology. While new discoveries are conveyed routinely, it is important for a therapist working with this population to keep current with new information and how it affects their clients with fibromyalgia.

It is clear that having a positive support system is a key factor in increased functioning and better management of symptoms for fibromyalgia patients. The research indicates that for many with fibromyalgia there may be a lack of this essential component of their care. The high divorce rate, maladaptive relationships and a medical community with limited options for care could leave some with only a negative support system. For many, a therapist may be their only source for essential positive support.

My own experience with a therapist who was familiar with fibromyalgia syndrome when I displayed symptoms was invaluable to me. It was in her office where the pieces of the fibromyalgia puzzle were falling into place. I remember the day she said to me, “I think you may have something called fibromyalgia” I immediately said, “No I don’t!” because I had heard of it before – there was no cure and some said, “it was all in your head” – I did not want to deal with a condition like that. My therapist stayed with
me where I was at emotionally, understanding I was not ready to hear what was being said, then after nearly a year, I said to her “I think I have fibromyalgia.” What I realize now is the new chapter in our work had already begun. From her first mention of fibromyalgia my reaction was so strong because I already knew deep down that it was true.

My therapist helped me through a grieving process that is unique to those of us who are diagnosed with a chronic, not terminal life altering condition. We systematically see the things that we were capable of doing in the past being removed from our reality. Chores become much harder until they are not possible to do and things we like to do become chores. For me, just the act of getting ready for the day can be a challenging process, I have had to buy special three foot long wash cloths to wash myself because my range of motion is limited due to pain. I then have to take breaks while using the blow dryer on my hair because of the combination of exhaustion and pain from lifting my arms over my head for any length of time.

There are better days and not so good days but my therapist is there to validate and support me when I talk to her about how much better I am feeling or how awful I feel since I had to go to the emergency room because I “over did it” cleaning my house. This grief work and validation is an ongoing process because it does not end; we are not working towards a good death we are working towards managing a changed life.

The most valuable work my therapist does with me, which has helped me to maintain my dignity and to achieve goals I may not have taken on even before I was diagnosed, is the work on my Self. This work touches on all the possible reasons I have fibromyalgia in the first place. For me shame and judgment were themes that I was
working on before diagnosis, once diagnosed these themes persisted in the foreground. With my diagnosis, I was simultaneously physically immobilized from my defense of overcompensation to adjust for shame and judgment and I was given many things to be judged for.

My hardest struggle has been with my family and balancing their expectations of me with my expectations of myself and what I need to do to reduce fibromyalgia symptoms and flare-ups. This is an ongoing struggle that leaves everyone feeling shame and as if their needs are not being met. I honestly do not know what my life would be like if I did not have the unconditional support of my therapist during the times when I am feeling the most like a failure as a wife and mother.

I have in my therapist an unconditional support system, she is non judgmental yet is not afraid to challenge me for my own growth. She validates my experiences and yet always expects me to acknowledge and take responsibility for my part in my own reality. There is a symbiosis of trust that my best interest is always at the center. There is always respect paid to my level of ability to do the work, it is on my time not hers. She is there to support me when the darkness momentarily takes over. She knows the stressors and triggers of fibromyalgia symptoms and, for example, reminds me that the weather has changed dramatically and that I usually have trouble with that when I come in upset that I am not feeling well. I feel that because I have her support, I am really able to appreciate the days that my pain is at a lower level and make the most out of everyday because I feel safe to really grieve the days when my pain is at a high level. Interestingly, because I am safe with her to really vent my frustration at my diagnosis, I find I rarely feel the need. I try instead to focus on what I can do rather than what I can not, if I am having a high pain
day then I try to appreciate the time I spent cuddling with my dog and watching a movie or taking a nap – I remind myself that I am doing this to take care of myself. My therapist reminds me that I am worth it.

**Future Work/Research**

It is important to point out that the evidence presented focused heavily on fibromyalgia patients with a history of trauma and that not all fibromyalgia patients share this history. It would be of interest to study the correlation between fibromyalgia patients with and without trauma histories with depression and suicidality.

In addition, although touched on in this writing, more in depth research can be presented on the financial consequences of fibromyalgia syndrome for both the patient and society. Including but not limited to medical care costs, social security disability, state disability, time missed at work, and long-term mental health care costs.
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