THE EXPERIENCE OF LIVING WITH FIBROMYALGIA FOR WOMEN IN NEWFOUNDLAND: A PHENOMENOLOGICAL STUDY

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THE EXPERIENCE OF LIVING WITH FIBROMYALGIA FOR WOMEN IN NEWFOUNDLAND: A PHENOMENOLOGICAL STUDY

by

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A thesis submitted to the School of Graduate Studies in partial fulfilment of the requirements for the degree of Master of Nursing

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ABSTRACT

Fibromyalgia (FM) is a complex, chronic, painful musculoskeletal syndrome which is characterized by extreme fatigue, disordered sleep, and other associated physical and cognitive problems. Because its etiology is unknown, and because no specific pathophysiological mechanisms have been found to underlie the syndrome, making a diagnosis is very difficult. FM adversely affects the quality of life, and the societal costs based on medical expenses, lost wages, lost tax revenue and compensation expenditures are very significant.

The purpose of this phenomenological study was to describe, and enhance the understanding of the experience of living with FM. The participants included nine women ranging in age from 30 years to 56 years who had been diagnosed with the condition for more than a year. The data were collected by means of unstructured interviews. Thematic analysis, utilizing van Manen's (1990) methodology, identified eight themes: (1) pain - the constant presence, (2) fatigue - the invisible foe, (3) sleep - the impossible dream, (4) thinking in a fog, (5) dealing with a flare-up, (6) longing for a normal life, (7) the power of naming - seeking a diagnosis, and (8) living within the boundaries. These themes were integral parts of the whole story, and through their interrelationships, the essence "confronting an invisible disability" was captured.

Those who administer the health care system will experience many challenges as they face the new millennium, and one of these challenges will be how best to cope with the increasing number of persons with a chronic illness. The findings of this qualitative research study about fibromyalgia, a chronic illness, have implications for future nursing practice, education and research, and consequently for the health care system in general.

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DEDICATION

This work is lovingly dedicated to the memory of my parents, William C. Sturge and Margaret (Sturge) White, teachers, preachers, and philosophers, who taught me many valuable lessons. Two of these lessons have inspired this project: (1) aim high and (2) learning is a lifelong experience. Thank you especially to mom for inspiring me to finish "my paper."

CHAPTER 1: INTRODUCTION

Chronic illnesses and disabilities represent major health challenges and account for most of the health care costs today (Lindsey, 1995; Thorne & Robinson, 1989). As a consequence, there is a vast amount of information pertaining to many chronic illnesses in general, and some chronic illnesses in particular. The information addresses to a limited degree what it is like to live with these conditions. However, despite the abundance of information pertaining to many chronic illnesses, very little is known about what it is like to live with the chronic debilitating condition of fibromyalgia (FM).

The purpose of this study is to increase the understanding of what it is like to live with FM. This understanding is facilitated by an exploration of individual experiences about living with this condition. The women in this study describe their struggle to live meaningful lives. Daily they face hurdles such as pain, fatigue and other related symptomatology, disruption in their plans, constant life style changes, continual flare-ups, and impaired physical and cognitive functioning. As these women describe their experiences of dealing with the enigma of symptoms, symptoms which necessitate making changes in all aspects of their lives, their descriptions help to explain what it is like to have this chronic illness.

Lack of knowledge about this syndrome is attributed to the fact that FM is a poorly understood form of a non articular rheumatic condition and consequently some medical practitioners even question the existence of the syndrome. Therefore, FM is very difficult to diagnose and equally difficult to treat. Additionally, the treatment, while intended to relieve the symptoms, often contributes significantly to many disruptions of normal daily living. The difficulty and uncertainty surrounding the diagnosis and treatment of FM increase the complexity for persons dealing with the syndrome. Each day they face this chronic condition and the associated symptoms about which very little is known and even less understood.

Background Information

FM is characterized by symptoms of widespread musculoskeletal pain, fatigue, stiffness, and a sleep disorder (Bennett, Smythe, & Wolfe, 1989; Johnson, Collo, Finch, & Felicetta, 1990). The hallmark of FM is the absence of joint inflammation in spite of persistent articular pain. The areas most commonly affected by the pain are the peri-articular regions of the muscles, at the insertion points of tendons and ligaments, and in the soft tissues surrounding the joints. The symptoms of pain, fatigue, stiffness, and a sleep disorder, along with associated cognitive disabilities, bowel and bladder spasms, migraine headache, allergies, tingling of hands and feet, rashes, blurred vision, and vertigo, make the process of establishing a definitive diagnosis very difficult. This difficulty is understandable since many of these symptoms are also common in other conditions (Cohen & Quinter, 1993; Duna & Wilke, 1993; Henriksson, 1994; Sherman, 1992; Smeltzer, 1987).

FM commonly affects approximately 10% to 15% of the general population but predominately affects women with a ratio of 10:1 as compared to men (Gerecz-Simon, Kean, & Buchanan, 1991; Harvey, Cadena, & Dunlap, 1993). The age of onset varies and it is usually reported to be within the age range of 20-50 years. This age represents the time in one's life when the majority of individuals are very productive in terms of contributing to society. Nevertheless, early signs of FM may appear during childhood, and are presented as increased complaints of "growing pains" and unusually sore muscles after playing sports (Johnson et al., 1990; Waylonis, Ronan, & Gordon, 1994; Romano, 1988). FM has been described in most countries of the world, it has no known ethnic bias, and its occurrence does not seem to be influenced by the type of climate (Bennett, 1995).

"Pain all over" is the primary complaint which causes clients to seek medical attention. The descriptions of the intensity of the pain vary from being moderate to severe, and the pain is either intermittent or continual in nature. The pain is more severe at specific tender point sites located symmetrically throughout the body. Some clients also report feelings of swelling at particular joint locations, however, this swelling is not found on physical examination (Harvey et al., 1993; Romano, 1988; Sherman, 1992). Most disturbing for many persons with FM is how to deal with the inability to concentrate, to compute simple problems and to remember names, addresses or specific dates. Many researchers attribute this loss of cognitive ability to the profound and ever present fatigue that is being experienced (Bennett, 1989; Gerecz-Simon et al., 1991).

Each day, persons diagnosed with FM face multiple challenges. These challenges include changes in lifestyles, threats to self-esteem, disruptions of usual roles, and decreasing physical, emotional, and financial resources. These daily challenges can cause the chronically ill person to experience many negative emotions such as anxiety, helplessness, anger, and loneliness. Frequently, these emotions are also experienced by other family members since in a way they also live with FM (Steinman-Kaufman, Fox, & Swearengen, 1990; Collier, 1990).

Knowledge about FM and an understanding of what can be done to assist persons to live with FM are the cornerstones for any educational program for the patients and significant others who are also directly affected by the diagnosis (Bennett et al., 1991). Therefore, the value of education programs should not be overlooked. My frequent conversations with patients with FM revealed that learning about the condition and becoming familiar with the symptoms gave them a new lease on life. Several articles supported the suggestion that a well-educated patient, one who is able to manage and make adjustments to schedules based on frequent fluctuations of symptoms, is as essential to the chronic illness management team as any doctor, nurse, psychologist, or social worker (Bennett et al., 1991; Masi, 1994; Cunningham, 1996).

Lorig and Holman (1993) described research studies which identified the positive outcomes of educational programs for arthritis patients. Lorig, Mazonson and Holman (1993) suggested that increased knowledge of one's illness resulted in long-term reduction in physician visits and health care costs for active program participants. The value of education for patients with FM cannot be underestimated since they must learn new ways of coping, pacing activities, and developing new means of changing the work environment for those who are gainfully employed (Wolfe, 1993). Disability payments, as a result of FM, were estimated to be $200,000,000 per year in Canada (McCain, Cameron, & Kennedy, 1989). With astounding costs such as these, research into FM is timely.

Rationale for the Study

The impetus for this particular study comes from three main sources: nursing experiences encountered during the advanced clinical practice component of the Master of Nursing Program, changes in the health care system which are placing more emphases on health promotion activities and patients as active participants in their care, and the scarcity of research on patients' perspectives of living with FM. In my nursing practice, on a rheumatology unit, I frequently observed the frustrations caused by a lack of knowledge and understanding about the syndrome by both patients and health care providers. Patients became frustrated by the lack of a clear diagnosis despite the seemingly endless battery of tests and examinations, and some patients felt that health care providers believed that their symptoms were imaginary. Health care providers became frustrated because complete remission from symptoms was rarely seen despite various treatment interventions.

The second motivating factor for this particular research is to help patients become active participants in their care. Patients are often discouraged by a lack of response to their treatment regimen, and lack an understanding of what is happening to them. Many patients are often unable to return to their employment, compounding the problems caused by FM. As nurses, we must assist persons diagnosed with chronic illnesses such as FM to become active, rather than passive, participants in the management of their symptomatology, as well as in other areas of health promotion. Understanding the condition is a first step in this direction.

In view of the need to help patients become active participants in their care, I assisted a multidisciplinary team to address the educational needs of patients with FM. The multidisciplinary team developed an educational program, and I co-facilitated the sessions with a physiotherapist and an occupational therapist. The topics we addressed in the program were general information about FM, medications and alternate treatments, sleep disturbances, nutrition, relationships, sexuality, the pain cycle, stress management, exercise and posture, communication, lifestyle changes, and energy conservation. In addition to being involved in the education program, I also facilitated at a self-help group. This group met once a month with the aim of providing information and education to persons with FM and their families in a non-judgmental, non-threatening environment. At each meeting, time was provided for group discussion followed by a question and answer period to address the participants' concerns.

Both my practice and involvement with patients with FM led me to search the literature for information about the condition which would assist professionals and patients in understanding this syndrome. This understanding was necessary in order to help patients become active participants in their own care. While there has been increased information about the incidence, etiology, pathophysiology, diagnosis and treatment of FM, I found little research into how this condition affected peoples' lives and what they experience as a result of having FM. As a consequence, and because women are far more likely than men to be diagnosed with FM, I planned this phenomenological study.

Purpose of the Study

The purpose of this study is to provide nurses and others who read this text with a clearer understanding of the meaning of living with FM from the women's perspective. This understanding may better prepare nurses and other health care providers in assisting women suffering from this chronic, painful condition in making choices to enhance their quality of life. Naegele (1992) suggests that enhancing people's capacity to cope effectively with chronic conditions is perceived to be a major challenge, both for those who have the chronic condition and for those immediately involved with them.

Since this is the first study undertaken in Newfoundland which describes living with FM, the results will be very important in providing baseline information into how women have experienced living with the symptoms. It is hoped that an interest will be sparked for further research into areas of health promotional activities for persons with disabilities and chronic illnesses. Since Canada's health care system is undergoing major restructuring, there is a gradual shift toward a greater emphasis on patient involvement, health promotion, and self-management of chronic illnesses (Jenny, 1990). Persons with chronic illnesses are living longer than they did in the past, therefore, nurses must be involved in developing effective plans of care to assist persons with a chronic illness to live a healthy life in spite of the illness (Finfgeld, 1995).

Nurses are in a pivotal position to contribute to health promotion and protection, not only for the healthy and acutely ill, but also for those with a chronic illness. Therefore, we need to be sensitive to the physical, mental, emotional, and spiritual needs of persons with a chronic illness. Results of this research will provide information which will assist nurses in acknowledging the importance of health promotion for persons with a chronic illness such as FM.

Information obtained from related life experiences may provide crucial data which can be considered when reorganizing essential services for these persons. Clients need to have increased control over the condition if they are to become personally involved in their treatment. This personal involvement may improve their overall health. According to Lorig and Holman (1993) there are overall improvements in health of the chronically ill persons when these individuals become actively involved in managing their own condition by making informed choices, and adopting new outlooks and health behaviors. Two positive outcomes from personally managing one's chronic illness are improved health status, and a reduction in the utilization of health care services. It is anticipated that the results of this research study will contribute in a meaningful way to this developing area of "health within illness" (McWilliams, Stewart, Brown, Desai, & Coderre, 1996). Therefore, this study which will describe the meaning of living with FM from the perspective of women who have this condition, will answer the research question "what is it like to live with FM?"

CHAPTER 2: LITERATURE REVIEW

Just how long fibromyalgia (FM) has affected human beings is not known. However, we do know that early references to the triad of pain, sleep disturbances, and fatigue have been around for a long time. Accounts of these symptoms were described in The Holy Bible, Job 7:3-4 & Job 30:16-17 (Harvey et al., 1993). According to Power (1993), Hippocrates (460BC - 377BC) also wrote about "lighter pains" which did not cause swelling or appear to be associated with gout. She also suggested that tenderpoints, which are crucial in making an accurate diagnosis of FM, were first defined by Balfour in 1824 but received little attention in the medical community for the next century.

Early in the 1900s, Sir William Gowers used the term 'fibrositis' to classify the chronic soft-tissue condition (Wilke, 1996; Wolfe, 1988). Gowers later acknowledged that the condition he had described did not meet the criteria for this definition since there was no evidence of infection or inflammation in the tissues. The term fibrositis was replaced by 'fibromyalgia' which means "a painful state of muscles and fibrous tissue" (Cunningham, 1996, p. 33). Since the mid 1980s a number of studies on FM or different aspects of FM have been conducted. However, most of the recent literature has been quantitative and focused on selected aspects of the condition such as pain, fatigue, sleeplessness, psychological factors, and patients' perception about lack of pain control. All these aspects influence the activities of daily living for persons with the chronic illness of FM.

Generally, studies that examined the clinical manifestations of FM, addressed how the symptoms affected the quality of life for those dealing with the symptoms, and compared FM with other rheumatic condition. Accordingly, this chapter is divided into four sections. The first section addresses the clinical manifestations of FM. The second section examines research which specifically focuses on the symptoms associated with living with FM. The third section is a review of the literature which compares FM with other rheumatic conditions, while the fourth section discusses the limitations of the research.

Clinical Manifestations of Fibromyalgia

Etiology and pathophysiology

The etiology and pathophysiology of FM are not fully understood. Rice (1986) postulated that the generalized experience of pain and tenderness may be caused by referred pain, muscle tension, and muscle spasm, and suggested that impaired pain modulation or alteration in the ability of the central nervous system to inhibit pain stimuli may be implicated in the pain severity. Subsequent to Rice's findings, Bengtsson and Henriksson (1989) described several studies which investigated muscle morphology, chemistry, and physiology in order to understand the most prominent symptoms of FM, pain and fatigue. Their results indicated disturbed microcirculation, mitochondrial damage, and a reduced content of high energy phosphates in persons diagnosed with FM.

Persons suffering from FM demonstrated abnormalities in stage IV non-rapid eye movement (NREM) of the sleep pattern. NREM sleep stage is important for the restoring and replenishing neurotransmitters which are vital in maintaining the human body in a state of balance or homeostasis. It was hypothesized that the abnormal sleep pattern interfered with the release of a growth hormone (GH), an essential factor in the restoration of normal muscle. A decrease in GH may not only cause fatigue but may exacerbate muscle deterioration (Bennett, 1989).

Russell, Michalek, Vipraio, Fletcher and Wall (1989) discovered that the serum level of serotonin was lower than normal in patients with FM. When serotonin is depleted there is a decrease in NREM sleep and an increase in somatic complaints. Deficit serotonin levels may also explain the increased presence of substance P, the neurotransmitter which interprets sensory stimuli and heightens awareness of pain perception. Painful muscles, muscle lesions, and spasms may also be caused by hypoxia which result from an abnormal vascular perfusion of these muscles often referred to as "microtrauma" (Bennett, 1989; Duna & Wilke, 1993). Bennett further suggested that the decreased perfusion may result from either lack of exercise to these muscles or a genetic predisposition to muscle microtrauma.

Despite general uncertainty about causal factors, what is known is that most persons are diagnosed with FM following physical or emotional trauma, a viral or bacterial infection, a general anesthetic or the birth of an infant (Boissevain & McCain, 1991; Harvey et al., 1993). However, the exact role of these events in the development of FM is still very speculative. For years FM was mistakenly thought to be the result of a psychological condition; yet, evidence has since demonstrated that patients with FM are no more depressed or anxious than those with other chronic, painful, debilitating conditions. It is now believed that depression and anxiety, when present, are the result of and not the cause of FM (Bennett et al., 1989; Clark, Campbell, Forehand, Tindall, &

Bennett, 1985; Hudson & Pope, 1989; Goldenberg, 1986, 1989; Kirmayer, Robbins, & Kapusta, 1988).

Diagnosis and treatment

The uncertainty by members in the scientific community as to the exact cause of FM means the process of making a diagnosis is very difficult. It is accepted, however, that there is an interplay between the biochemical, immunological, psychic, and the neurological systems (Boissevain & McCain, 1991). Currently there are no specific laboratory or radiological tests available to assist in making a diagnosis. Therefore, the examining physician must rely on the client's medical history and the physical findings present during examination. Palpation of specific muscles and the surrounding area will reveal tender points at specific locations in persons with FM.

In 1990, The American College of Rheumatology established specific classification criteria to assist in making a diagnosis of FM. These criteria included the presence of tenderness in 11 out of the 18 standard locations. The locations are identified as:

Occiput: bilateral, at the suboccipital muscle insertions.

Low cervical: bilateral, at the anterior aspects of the intertransverse spaces at C5-C7.

Trapezius: bilateral, at the midpoint of the upper border.

Supraspinatus: bilateral, at origins, above the scapula spine near the medial border.

Second rib: bilateral, at the second costochondral junctions, just lateral to the junctions on upper surfaces.

Lateral epicondyle: bilateral, 2 cm distal to the epicondyles.

Gluteal: bilateral, in upper outer quadrants of buttocks in anterior fold of muscle.

Greater trochanter: bilateral, posterior to the trochanteric prominence.

Knee: bilateral, at the medial fat pad, proximal to the joint line (Wolfe et al., 1990, p. 171).

Approximately four kilograms of pressure must be applied to a tender point by the physician, and the patient must indicate that the tender point locations are painful, and not merely tender.

In addition to the presence of the required number of tender spots, a history of widespread, musculoskeletal pain lasting longer than three months in all four quadrants of the body (widespread pain means pain above and below the waist and on both sides of the body) must be experienced. The absence of other systemic diseases, such as rheumatoid arthritis (RA), lupus, thyroid problems or cancer must be established, since any of these diseases could be the cause of the underlying pain (Wolfe et al., 1990). Geel (1994) reported that the criteria established by the American College of Rheumatology was adequate to identify FM with a sensitivity of 88% and a specificity of 81%.

Many of the complaints associated with FM are so general that they mimic those of many more serious, life-threatening conditions. Therefore, making a correct diagnosis is time consuming and stressful for both the client and physician. Many clients undergo complicated, and repeated clinical examinations and a seemingly endless battery of tests before a diagnosis is made. Discussions with clients diagnosed with FM confirm that there are frequent referrals to several specialists. As well, many of these clients sometimes become frustrated with the lack of medical information they receive, and often report feelings of not being taken seriously by their doctor as they report their many vague signs and symptoms.

At present, treatment for FM is directed toward managing the symptoms. Since signs and symptoms, and the levels of severity are highly individualized, the treatment plan must be tailored to meet individual needs. In terms of effective management of FM, these different levels of symptom severity make the treatment frustrating for doctor and patient (Silverman, 1994). The single most important treatment intervention is a comprehensive explanation of the condition (Doherty & Jones, 1995). This intervention, in effect, helps by creating a trusting relationship between doctor and patient and by alleviating, for the patient, any previous misconceptions that the symptoms are "all in the head". It is helpful for the clinician to explain that FM is a common, chronic, painful condition, thus informing the patients that they are not alone with this condition. Additionally, while explaining that FM can decrease the quality of life, it is essential to explain that this condition will not lead to joint destruction or deformities, and it is not life threatening (Carette, 1996).

FM is treated by the following classification of medications: medications that improve sleep such as a low dose of a tricyclic agent, medications that promote muscle relaxation, and medications which are helpful in reducing pain, including the non-steroidal anti-inflammatory drugs. These latter drugs must be used cautiously since they can cause gastrointestinal problems. Additionally, other analgesic medications may be used for chronic pain relief. Narcotic analgesics are not recommended for pain control since FM is a long-term condition and extended use can contribute to drug dependency. These drugs are reserved for severe, painful flare ups of the condition. Likewise, drugs classified as benzodiazepines, which effectively treat muscle spasms, are also used cautiously. These drugs, as with narcotics, may cause physical dependency. Additional interventions which assist patients and their families to cope with FM include exercise programs to improve muscle stretching and cardiovascular fitness, relaxation techniques, education, and self-help programs (Rothenberg, 1995).

The successful FM treatment plan involves the inclusion of a variety of medical and other health care professionals. Patients benefit from a coordinated team approach which fosters realistic goal setting by the team members in conjunction with the patient. Therefore, patients must remain active participants in the plan of care which has been devised to suit their specific needs (Bennett et al., 1991; Masi, 1994).

Symptoms Associated with Fibromyalgia

Pain is the hallmark characteristic symptom of FM and must be present for a positive diagnosis (Bennett, 1995). Prior to the development of the 1990 diagnostic criteria for FM, it was almost impossible to do comparative research with other conditions. A study by Wolfe et al. (1990) laid the foundation for the criteria for the classification of FM according to The American College of Rheumatology, and expanded on earlier studies by Smythe and Moldofsky (1977) and Yunus, Masi, Calabro, Miller, and Feigenbaum (1981). Wolfe et al. studied 588 consecutive patients who were recruited from 16 centres in the United States. Of this group, 293 participants had FM, and 265 participants were used as a control group. Results indicated that 97.5% of patients with FM complained of widespread pain compared to 71.8% of the chronic pain control group. As well, 59.5% of patients with FM had more than 15 painful locations compared to

13.3% of the control group. Of the patients with FM, 68.8% complained of generalized pain as compared to 21.7% of patients in the control group. Reports indicated that the pain was often described as either axial or diffuse in location, either constant or intermittent, and either dull, nagging or exhausting.

Hagglund, Deuser, Buckelew, Hewett, and Kay (1994) investigated the relationships among weather conditions, disease severity and symptoms for persons with FM. Eighty-four subjects completed the Weather and Pain Questionnaire (WPQ), the Arthritis Impact Questionnaire (AIMS) and a Visual Analog Scale (VAS) assessing pain. Subjects reported that weather affected their musculoskeletal symptoms. The strongest relationship was found between weather beliefs and self-reported pain scores. These investigators concluded that although patients with FM believed that weather worsened their symptoms, it was unlikely that physiological changes were associated with actual weather conditions. These results were consistent with the effects of the changing weather conditions on patients with FM reported by Wolfe et al. (1990) and Yunus et al. (1981).

Pellegrino (1990) studied atypical chest pain as an initial presentation of FM pain. Pain associated with FM can have a variety of presentations and characteristics, so FM should be suspected in patients presenting with atypical chest pain. As well, dyspnea is a common symptom in severe cases of FM. Caidahl, Lurie, Baka, Johansson, and Wetterqvist (1989) investigated the prevalence of dyspnea according to a 5-grade score proposed by the World Health Organization among 87 women diagnosed with FM. The study suggested that dyspnea was common among patients with FM and was not explained by cardiac or pulmonary causes, but may be partly due to diaphragmatic muscular insufficiency and physical inactivity.

Irritable bowel syndrome (IBS), another associated condition which affects a large majority of persons diagnosed with FM, has not received much attention in the research literature. Although many authors have referred to IBS when describing the complex condition of FM, only two articles were found which specifically addressed this disease (Romano, 1988; Yunus, Masi & Aldag, 1989). Romano (1988) investigated the relationship between FM and IBS by examining 300 patients who were divided into three groups of 100. Group I consisted of patients who fulfilled the criteria for FM and who had no other associated condition. Group II patients had an arthritis disorder as well as a sleep disorder and some tender spots. Group III consisted of patients diagnosed with arthritis without any symptoms of FM. IBS was diagnosed in 49% of Group I, 19% of Group II, and in 9% of Group III. Yunus et al. (1989) studied 113 patients with FM, 77 patients with RA and 67 healthy controls. These authors found evidence to support the increased prevalence of three functional syndromes (irritable bowel, chronic headache, and dysmenorrhea) in the FM group as compared with RA and the normal control group. The results of these studies suggested that FM symptoms were not confined solely to the musculoskeletal system.

Although the majority of studies reviewed were concerned mainly with the issue of pain and disability, one study investigated the sleep complaints in FM. Jennum, Mohr-Drewes, Andreasen, and Dremstrup-Nielsen (1993) evaluated the sleep structure and complaints including snoring, mood, depression, memory, and concentration of 20 patients with FM and compared them to a healthy matched population. Findings of this study suggested that the patients with FM did not sleep as well as the control group due to higher occurrences of arousal which resulted in mood swings, depression, fatigue and decreased levels of concentration.

Effects of symptoms on daily living

More recently, researchers have investigated how the symptoms of FM affected women's activities of daily living (Henriksson, 1994; Henriksson, 1995; Henriksson, Gundmark, Bengtsson, & Ek, 1992; Ledingham, Doherty, & Doherty, 1993; Schaefer, 1995). In the study by Henriksson et al. (1992), they found that FM symptoms had a pervasive negative influence on activities of daily living. As a result of the pain, fatigue and associated conditions, employment, personal care, and leisure activities were very difficult to perform, requiring respondents to modify habits and routines.

Henriksson (1994) designed a descriptive correlational study to investigate how patients with FM perceived their symptoms and their consequences for everyday life. These results were compared to a similar study performed by Bengtsson et al. (1986). A convenience sample of 56 patients answered a demographic questionnaire and the Sickness Impact Profile. Results indicated that symptoms of FM influenced all aspects of everyday life and caused pronounced negative physical, mental, social, and financial consequences on work, family life, and leisure.

Ledingham et al. (1993) used a descriptive correlational study to examine outcomes in terms of symptoms, functional impact, and development of other diseases in a convenience sample of 72 patients, previously diagnosed with FM. Results indicated poor outcomes for patients with FM and an association with marked functional disability and high levels of anxiety and depression. All these factors had a negative impact on the functioning of the family. Based on the nature of the study's design, findings did not confirm whether or not psychological problems were causal factors in FM, or influenced the ability to cope with the consequences of the condition. It was shown that anxiety and depression positively correlated with the severity of the condition. This information confirmed that more effective health interventions are obviously needed for this common and disabling syndrome.

A study by Henriksson (1995) focused on the patient's perspective of living with chronic muscular pain and factors that explained and gave further understanding of how the condition influenced everyday life. The participants included 40 women with FM who lived in two different cultures which had different types of health care systems. The American women, all white, were recruited from a rheumatology clinic and the Swedish group was matched from the files of a rheumatology clinic, or at a pain clinic of a university hospital. Results of the coding and sorting of the taped interviews revealed three typologies: (a) encounters, (b) consequences, and (c) strategies. The analyses suggested that family members experienced problems with accepting their changed lifestyle. Role incompetencies were another problem because these women had to relinquish their role as primary homemaker. Martial relationships were strained as a result of their being "too tired" plus the painful sensation of physical contact by another. These problems intensified the FM symptoms. Others reported that as family members became informed about the condition, more understanding and support were evident. This study by Henriksson confirmed the necessity of getting an early diagnosis and the importance of educating the patient and the family concerning FM.

Schaefer (1995) used a grounded theory study to describe how 36 women lived with FM. The participants were obtained through community programs on chronic fatigue syndrome and related disorders and through the use of snowball sampling. Each participant was interviewed, some interviews were taped recorded and transcribed verbatim, others were immediately recorded from notes and memory. Data were analyzed using the constant comparative method of analysis. The findings described the constant struggle of patients with FM as they fought to maintain balance in their lives. Not only were the women's lives affected, but also the lives of family members and significant others. Several women gave up the struggle as their condition became unmanageable and out of control. Others, with the help of supportive family and friends, allowed FM to be only a small part of their lives, as they moved on.

Other researchers were interested in how patients with FM viewed their lack of control over pain and other symptoms, and how they coped with the constant presence of symptoms (Buckelew et al., 1994; Buckelew et al., 1996; Nicassio, Schoenfield-Smith, Radojevic, & Schuman, 1995). One study of patients with FM focused on self-efficacy and adjustment to chronic pain and illness (Buckelew et al., 1994). In this descriptive correlational study, the relationships between pain behaviors and psychological variables, including self-efficacy and depression, were examined with 73 participants who met the classification criteria for the diagnoses of FM by American College of Rheumatology. These participants were recruited by physician referral and by newspaper advertisements. Findings from the study revealed that depression alone did not predict pain behavior over and above the myalgic scores and age. However, in three separate analyses, self-efficacy for functional pain and other symptoms each predicted pain behavior over and above myalgic scores and age. These results indicated that as self-efficacy scores increased, the total pain behavior decreased.

Nicassio et al. (1995) evaluated the pain coping ability, using cognitive and behavior tendencies, of a group of 69 patients twice during a three month period. Results of this study showed the importance of pain coping strategies by these patients. Low perceived pain control negatively contributed to actual pain control. Since treatment interventions for patients with FM were individually tailored, it was suggested that interventions should address specific maladaptive actions. Therefore, cognitive restructuring strategies which enhanced self-efficacy and perceived control over pain may affect a positive response for patients with FM.

Buckelew et al. (1996) examined whether pretreatment self-efficacy and pre to post treatment changes in self-efficacy predicted post-treatment tender point index, disease severity, pain and physical activity among 109 participants with FM. Data were collected by assessing the patients before and after a 6-week training intervention. Methods of data collection included examination of the tender points, physicians' ratings of disease severity, the Visual Analog Scale for pain, the physical activities subscale of the Arthritis Impact Measurement Scales and the Arthritis Self-Efficacy Scale. Results of these tests revealed that higher levels of self-efficacy are associated with better outcomes and may mediate the effectiveness of treatment programs for FM.

Social support is thought to be a mediating factor for the effects of FM. It has the potential to serve as a buffer for or protection from further negative life stressors inflicted by a chronic illness (Deardorff, Rubin, & Scott, 1991; Fitzpatrick, Neuman, Lamb, & Shipley, 1989; Jamison & Virts, 1990; Lanza & Revenson, 1993; Revenson & Majerovitz, 1991). Two additional articles were found which made specific reference to the value of social support for patients with FM. While Bolwijn et al. (1994) compared patients with FM to patients with RA, Bolwijn et al. (1996) compared patients with FM to healthy controls.

Bolwijn et al. (1994) designed a descriptive study to investigate and describe trends in the personal social network structure of 10 patients with FM and 10 patients with RA. Data were collected by means of structured interviews. Findings indicated that the social networks were comparable in most respects, namely, small number of intimate friends, reliance for support on the spouse and physician, and fewer new social contacts. However, there was some evidence to support the view that social networks of patients with FM were more restricted than those of patients with RA.

In another related study, Bolwijn et al. (1996) investigated the social network characteristics and perceived loneliness in 25 patients with FM and 25 healthy controls. This cross-sectional, retrospective, case control design collected data using a structured interview and self-report questionnaire. Unlike the previous study, the results of this study indicated that patients with FM have more intimate friends and more health care providers than the control group. Patients with FM initiated more frequent contacts with family members than the control group and feelings of loneliness among patients with FM were not significantly different from the feelings of loneliness among members of the control group.

Comparison of Fibromyalgia with other Rheumatic Conditions

FM is classified as a rheumatic condition (Gerecz-Simon et al., 1991) and since many aspects of FM resemble some of the aspects of RA, many research studies compared patients with FM and patients with RA along a number of dimensions. Therefore, some of the literature also included other chronic pain conditions.

Leavitt, Katz, Golden, Glickman, and Layfer (1986) compared the pain properties of 50 FM subjects and 50 RA controls using the McGill Pain Questionnaire (MPQ). This research found that patients with FM scored higher, which meant that the number of words chosen to describe pain was higher than the number chosen by the RA group. Additionally, the FM group used more specific descriptors than the RA group to describe their pain. Perry, Heller, and Levine (1989) conducted a similar study using the MPQ with 19 polyarthritic patients and 17 patients with FM. In addition to the MPQ, Perry et al. administered the Visual Analogue Scale (VAS) and used terms like "no pain" and "worst pain ever". Results of the study indicated that patients with FM scored higher or indicated a stronger disposition to pain than did patients with RA. These two studies indicated that FM was a more painful condition than RA.

Other researchers were interested in how patients with FM felt about their pain control compared with other patients suffering from chronic rheumatic conditions. The descriptive correlational study designed by Pastor et al. (1993) examined the beliefs about lack of pain control, and the relationship between locus of control and health status in both patients with FM and those suffering from other chronic rheumatic diseases. Participants were recruited from an outpatient clinic of a rheumatology unit of a large hospital in

Spain, and the sample was divided as follows: FM = 32, RA = 32, serum lupus = 20, ankylosis spondylitis = 22 and osteoarthritis = 31. Results indicated that patients with FM believed that they could not control their symptoms nor could they influence the disease process by themselves. All subjects with FM, who demonstrated a tendency toward external locus of control and low self-efficacy, believed there was very little that they could do to affect changes in specific behaviors that could have positive effects on health outcomes. As well, these subjects exhibited a decreased sense of self-control which may explain the feelings of helplessness often reported by persons with FM.

Burckhardt, Clark, and Bennett, (1992) and Martinez, Ferraz, Sato, and Atra (1995) reported that pain was a common symptom in both FM and RA. Burckhardt et al. (1992) devised a study to replicate the work of Leavitt et al. (1986). The finding of their study revealed comparable pain descriptions to those identified by Leavitt et al. FM pain was described very similarly to RA pain, and both groups saw pain as a major contributing factor to their fatigue. The main difference between the groups was in the location of pain. Patients with FM indicated a more diffuse presentation as compared to those sites indicated by patients with RA. The extent of pain negatively impacted on the quality of life for both groups. Similarly, Martinez et al. (1995) evaluated the quality of life for patients with FM and RA. In this study 44 women with FM and 41 women with RA were clinically evaluated at the beginning of the study, and at three and six month intervals. Results disclosed that FM had a negative impact on the quality of life for FM and RA sufferers since both groups experienced clinical, functional, and economic problems related to their conditions.

Burckhardt, Clark, and Bennett (1993) designed a descriptive correlational study that examined and compared the quality of life of women with FM to the quality of life experienced by women with RA, osteoarthritis (OA), permanent ostomies (OST), chronic obstructive pulmonary disease (COPD), insulin dependent diabetes (IDDM) and healthy controls. The 280 participants were taken from a subsample of women who were part of a larger study of quality of life and divided accordingly; FM = 60, IDDM = 35; COPD = 27, OA = 41, RA = 31, OST = 29 and healthy controls = 49. Results revealed that women with FM consistently scored lowest on the quality of life measures as compared to women in other samples. These results suggested that FM may adversely affect quality of life to an extent not previously recognized, and possibly family relationship may be altered as the women contend with muscle pain, fatigue and disturbed sleep on a daily basis.

Gaston-Johansson, Gustafsson, Felldin, and Sanne (1990) designed an exploratory study to examine psychological factors associated with the consequences of chronic pain in patients with FM. The study compared 31 patients with FM with 30 patients with RA on feelings about self pain, support from significant others, psychosomatic symptoms, activities of daily living, job satisfaction and future expectations. Results demonstrated that patients with FM had more negative feelings about themselves, were more occupied with the disease, experienced more limitations with activities of daily living and experienced more negative pessimistic feelings about future employment than patients with RA. These findings demonstrated that support from significant others was not only similar for both groups but was also important in decreasing some of the stress. Social support was also useful in facilitating effective coping and in adjusting to the illness. This finding was of particular interest for patients with FM and others with an arthritic condition. The value of the contribution others can make in affecting positive attitudes to increase health and well-being must not be underestimated.

Limitations of the Literature Review

In reviewing research on FM, several limitations are evident. Articles which described research of a clinical nature did not always clearly identify the particular outcome measures that were being used. As well, the method of measurement for the outcome measure was not always identified. Most of the studies were descriptive correlational or exploratory in design, therefore, it was not possible to infer causal relationships. In some cases, terms or concepts were not always defined and many studies failed to inform the reader about the validity and reliability of the measurement instruments. Other limitations of the studies included failure to identify a conceptual framework and the utilization of small samples. As well, studies which particularly focused on other family member's reaction often did not identify the developmental stage of the family. The developmental stage of the family needs to be addressed if relationships between chronic illness, individuals, and family life span development are to be understood (Stuifbergen, 1990).

In many cases the data pertaining to pain severity were obtained solely by self-reports. While it is recognized that self-reports are most important in identifying severity of pain, for comparative purposes in research this form of data collection needs to be augmented by other objective or standardized measures of pain behavior. As well, some of the self-report questionnaires only measured improvement and did not consider whether or not the condition had deteriorated. In those studies where data were collected at various intervals, it is unclear whether or not dropouts were included in the final data analysis. Clearly, future studies must address these limitations in order to increase confidence in the research findings.

Summary of the Literature Review

Much research has been done on trying to delineate the symptoms, etiology and pathophysiology of FM especially looking for physical changes. Review of the literature indicates that the persistent pain, muscular fatigue and sleep disturbances have serious negative consequences for the quality of life for all patients with FM. It has been discovered that the serum level of serotonin is lower than normal in patients with FM and may be the primary reason for disturbed sleep patterns.

While there is uncertainty in the medical community as to the exact cause, and though a definitive diagnostic test does not exist, much has been done in an effort to establish diagnostic criteria. The classification criteria established by The American College of Rheumatology require the presence of tenderness in 11 out of the 18 standard locations, and the individual also must have a history of widespread, musculoskeletal pain in all four quadrants of the body lasting longer than three months.

Various studies involving patients with FM have focused on the symptoms associated with FM. Pain is the hallmark characteristic symptom and has received significant emphasis in most studies including research on the effects of weather conditions on pain severity and intensity. Research has also examined the relationship between associated conditions such as dyspnea and IBS.

Another focus of research studies is an examination of the effects of symptoms on daily living. In terms of both pain and global debility, those suffering with FM experienced more severe symptoms than those having other chronic pain syndromes. The serious consequences of FM negatively influenced other members of the immediate family in regards to social, leisure, and working activities. The other family members often took on additional responsibilities and adjusted to altered traditional family roles and duties. The literature, to a limited extent, addressed the concepts of social support and self-efficacy. It was suggested in the literature that all persons diagnosed with FM should adopt an exercise program if they hoped to control the symptoms. To be successful in achieving some degree of behavioral change, these patients must be goal-directed and persistent and must have some form of social support. Self-management of pain and compliance with a treatment program is highly dependent upon enhancing expectations about how to cope and adjust to the condition, rather than merely educating them about how these factors affect the condition (Taal et al., 1993).

A more recent focus of research is on the relationships between FM and other rheumatic conditions. There are indications that patients with FM have greater intensity and severity of pain that is more diffusely presented than patients with other rheumatic conditions such as RA. In the study by Gaston-Johansson et al. (1990), they indicated that patients with FM had more negative feelings about themselves, were more occupied with the disease, experienced more limitations with activities of daily living and were more pessimistic about future employment than patients with RA.

However, it should be noted that most of the studies which addressed FM were cross sectional and quantitative, and the dominant focus was on the short to long term consequences of FM, or its clinical nature. More qualitative research, such as that presented in this thesis, needs to be done to describe and interpret the core of the lived experience. This is one way to enhance health care providers' knowledge of the individual perspective of living with FM and should help to fill the gap left vacant by the existing FM research literature.

CHAPTER 3: METHODOLOGICAL APPROACH AND METHODS

This phenomenological study is designed to describe and to interpret the meaning of living with the chronic illness of FM for a group of Newfoundland women. This chapter consists of two major sections: methodological approach and methods. The first section presents phenomenological research as a methodology, and more specifically as a mode of inquiry described by van Manen (1990). The second section describes how I used phenomenology as a method to investigate the experience of women living with the chronic illness of FM.

Methodological Approach

Phenomenological research

Phenomenology, as a research methodology, is a rigorous, critical, systematic investigative methodology which has gained recognition in recent years and is viewed as "a qualitative research approach applicable to the study of phenomena important to the discipline of nursing" (Streubert & Carpenter, 1995, p. 29). Bergum (1989) describes phenomenological research "as a 'human' science which strives to 'interpret' and 'understand' rather than to 'observe and explain'"(p. 43). Based on these concepts, phenomenology appears to provide a closer fit conceptually with the types of research questions that arise in a clinical setting (Beck, 1994).

Professional nursing practice based upon scientific research requires a methodology which does not reduce the person being studied to an object with many smaller quantitative units. Therefore, phenomenology, a qualitative methodology, can effectively serve the nursing research goals of understanding the whole human lived experience. Oiler (1982) suggested that since nursing was concerned with lived experiences, phenomenology should focus on interpersonal techniques and the individual as being "author of his own world; definer of his own reality" (p. 178). The phenomenological researcher needs to describe the true meaning of the lived experience and transform the essence into a written phenomenological account made possible by the researcher's reflections and the participants' descriptions (Streubert & Carpenter, 1995).

The aim of phenomenology is to exemplify the meaning of human phenomena while understanding the meanings of lived experiences of everyday situations and relations. Research of this nature must begin in the life world, the world described by Husserl as the world of natural attitude of everyday life, original and pre-reflective (van Manen, 1990). In other words, phenomenological research attempts to question and gain insightful reflective descriptions into personal perspectives on a particular incident or on particular incidents. To successfully accomplish this process, van Manen (1990) described four existentials that can assist the researcher's inquiry into the ways experiences are perceived: lived space, lived body, lived time, and lived human relations. Simply described, these existentials form the foundation for all phenomenological inquiry. Lived space refers to the space felt within which a person moves; lived body refers to the physical bodily presence of someone in the world, that presence can both reveal and conceal something about the self at the same time; lived time refers to the temporal dimensions of the past, present and future. These three form the foundation of being in the real world, whereas lived relations are those relations maintained with others in shared interpersonal space. According to van Manen, these four existentials are dimensions of a lived experience that resist separation. They are the link which allows the researcher to truly understand the richness of meaning in a particular lived lifeworld or experience. In my study, the "lived body" and "lived relations" are of utmost importance to its very essence.

Phenomenology identifies this inseparable connection to the world of lived experience as the principle of "intentionality." van Manen (1990) described "intentionality" as the way a person is connected to the world. Gaining a deeper understanding of the nature or meaning of everyday experience by way of the principle of intentionality is at the core of phenomenological research. Although persons are not always aware of the principle of "intentionality," consciousness or awareness is the only access human beings have to the world. Through reflecting, the basic characteristics of consciousness are discovered, since "to be conscious is to be aware, in some sense of some aspect of the world" (van Manen, 1990, p. 9). Reflection on a lived experience is always recollective, and phenomenology attempts to extract meaning from experiences as described by individuals.

"Reduction" as discussed by van Manen (1990) is also integral to my research. Reduction involves the need to overcome subjective feelings, previous experiences, theories or scientific concepts that would prevent me from coming to terms with an experience. According to van Manen, reduction is "the ambition to make reflection emulate the unreflective life of consciousness" (p. 185).

In applying the principle of reduction, that is, by coming to terms with personal beliefs, understandings and biases, I developed a closer understanding of the phenomenon which allowed for true phenomenological research to begin. van Manen (1990) refers to this conscious effort to do "reduction"as "bracketing." Bracketing, the suspension of personal beliefs and values about the phenomenon, is necessary in order to study essential structures of the participants' world. van Manen further suggests that since presuppositions and assumptions may creep back into the researcher's thoughts, merely trying to forget them would likely be impossible. Therefore, he suggests that holding presuppositions and assumptions at bay while exposing them as barriers to an understanding, helps in assisting a researcher to come to terms with personal assumptions. Bracketing is an exercise that the phenomenological researcher works at consciously and vigorously while the lived experience is being investigated.

Many sources of experiential material in the form of interviews, observations, literature and art may assist the researcher in the quest to describe and understand the lived experience while bracketing occurs. To assist with this process, I read a variety of novels including *The body silent* (Murphy, 1990), *You are not your illness* (Topf, 1995), *Pain - The gift nobody wants* (Brand & Yancey, 1993), and *The man who mistook his wife for a hat and other clinical tales* (Sacks, 1984) and a poem entitled *Invisible person: Invisible pain* (Turnbull, 1995). These examples assisted me with the act of understanding and interpreting the phenomena of living with FM.

van Manen (1990) describes phenomenological research as consisting of six different activities which form a dynamic interplay within human science research. In following his six different research activities, for the initial step I chose a phenomenon of interest from my clinical area and formulated a phenomenological question. It was during this step in the phenomenological process that I 'bracketed' personal feelings and assumptions and made explicit understandings, beliefs, biases, assumptions, presuppositions and theories. Next, I explored the phenomenon by generating data while obtaining experiential descriptions from the research participants and not by personal conceptualization of the event. Following this activity, I attempted to identify essential themes which described the lived experience. This activity involved reflecting on the descriptions given by the participants, and required me to read and reread the text as the tapes played. I analyzed the thematic statements by utilizing the selective highlighting approach. This process is described by van Manen as identifying by highlighting, phases or statements which speak to or reveal something about the phenomenon being studied.

While I identified thematic statements, I wrote and rewrote the phenomenological text that described the lived experience. Throughout this activity, I remained focused on the research question and its purpose, thus not permitting myself to move too far from the purpose and intent of the research. This assisted me in not settling for anything less than that described by the participants. The final activity suggested by van Manen (1990) is "balancing the research context by considering the whole" (p. 33). It was this activity that assisted me to see how the parts fit together to describe the more complete picture of living with FM. It helped me not only to isolate concepts but to see a phenomenon as a lived experience.

In this phenomenological research the emphasis was always on the meaning of lived experience. Phenomenological research "borrows other people's experience and their reflection on their experience" (van Manen, 1990, p. 62). Therefore, this activity allowed me to understand more fully what living with FM meant in the context of these women's experiences. Thus, in this study I continually asked what something was really like. To accomplish this activity, I chose to engage in an unstructured interview or conversational relationships. This is the means through which experiential narrative material which allowed for a deeper understanding of the human phenomenon emerges as the conversation unfolded. It is essential that questions remain open and opinions are not given by the researcher (Carson, 1986). This type of data gathering assisted in developing a closer relationship with the participant concerning the meaning of the experience. As well, personal observations were used, while other forms of literature previously identified were used to a lesser extent.

The interview was purposely unstructured and questions did not direct the participant to a specific response. The phenomenological interview was an attempt to gain the necessary information by prompting the participant to reveal the story as it is experienced (van Manen, 1990). Silence throughout the interview was not considered detrimental to the interviewing process, but rather as a further attempt at reflection by the participant.

Self-discussion by the participant was only possible in as much as I communicated interest in understanding the participant's experience while suspending personal views of judgement (Knaack, 1984). Therefore, I consciously remained aware of the question and was not swayed or influenced by conversation which did not serve a specific purpose. Observation, properly utilized in this phenomenological research, allowed me to enter the real world of the persons being investigated as I became a direct participant of these persons' lifeworld. As well, as described by van Manen (1990), I maintained a close relationship and remained alert to situations which allowed for distancing and reflecting.

In human science research, it is necessary to write and rewrite the text to allow for reflection into the nature of particular lived experiences. Reflection can be best understood from two main sources; the participant's and the researcher's. While the participants reflected upon their life experiences by recalling and recounting the experiences, I reflected on the topic from the moment the specific phenomenon was chosen for study. The activities of bracketing personal feelings, listening to the taped interviews, writing the script, rewriting the written scripts, formulating themes, reviewing and discussing the meanings of the themes with others, and revealing the essence of the participants' meaning required my reflection on the particular life experiences.

Since it is not enough merely to reflect upon the meaning of the phenomenon under study, I searched for an understanding of the phenomenon. This understanding was accomplished by viewing the phenomenon by means of extracting themes. Themes, according to van Manen (1990) may be understood as the basis of the experience. As I analyzed a particular phenomenon, I engaged in the activity of uncovering the theme or themes that made the experience what it really was. Themes are seen as the tools which give "control and order to our research and writing" (van Manen, 1990, p. 79). Within themselves, themes can only shape and help to describe the content of the experience. Therefore, as a separate entity, themes will never completely capture the lived experience but will assist in the expression of an emerging notion or essence in a temporary and exemplary form. In other words, themes within themselves are the precursors to the essence of the life experience (van Manen, 1990).

As I identified the themes, I collaborated with the participants and other researchers to verify and generate deeper insights and understanding of the identified themes. By utilizing hermeneutic phenomenology, I attempted to develop the internal meaning of the lived experience to capture the essence of living with FM for a group of Newfoundland women. I endeavoured to be exact by aiming for interpretive description which totally described the most subtle details of living with the chronic painful condition of FM. However, I am aware that capturing total lived experiences is a complex process and according to van Manen (1990) definite descriptions are unlikely to be attained.

Methods

van Manen (1990) described methods as a "certain mode of inquiry" (p. 28). This mode of inquiry is the particular way which allowed me an understanding into the nature of the phenomenon. The detailed description of phenomenology as a human science approach described by van Manen served as the tool which guided me in this study in exploring the experience of women in Newfoundland living with FM. Data were analyzed following interviews with nine women who lived with the condition. This section describes methods of participant selection, interview procedures, theoretical consideration, and data analysis techniques.

Participants

Participants in this study were women who had been diagnosed with FM. The inclusion criteria required that the women (1) be diagnosed with the condition for at least one year; (2) be in the age range of 20-57; (3) have a primary diagnosis of FM; and (4) understand spoken English, as well as be fluent in English. Rationale for these criteria was based on the following assumptions: (1) FM predominantly affects women, therefore, women were more readily accessible; (2) being diagnosed with the condition for a period of at least one year ensured that the participant had lived with FM long enough to give insight and meaning into the experience of living with FM; (3) the age range selected corresponded with the age cited in the literature for women afflicted with FM; (4) the primary condition was FM which ensured that the area studied was the phenomenon of living with FM rather than some other condition; and (5) the participants understood and spoke English since it was the language of the researcher. The last criterion reduced the possibility of confusing or misunderstanding information being conveyed throughout the interviewing process.

Selection of participants

According to Streubert and Carpenter (1995), purposeful sampling is used most commonly in phenomenological research. Through this method of sampling individuals are selected for the study based on their particular knowledge of the phenomenon. It was important for this study that the participants were introspective and self reflective about their experiences. As well, it was necessary for them to articulate clearly these experiences to me.

The nine participants involved in the study were selected from names of women who attended a six-week educational program offered as an outpatient program at a tertiary care hospital in St. John's, Newfoundland. I, along with staff from physiotherapy and occupational therapy departments, co-facilitated this education program. Hence, accessing appropriate participants was not a problem since records of these participants were kept in the files of the Physiotherapy Department. This sample size was considered adequate for a phenomenological study, since a study of this nature involved a large volume of narrative data collected through interviews and observation (Morse, 1989; Sandelowski, 1995; Streubert & Carpenter, 1995). A physiotherapist, who co-facilitated this education program, was consulted for participant selection. Approval for the involvement by the physiotherapist was obtained from the Director of the Physiotherapy Department (see Appendix A).

The prospective participants were contacted by the physiotherapist either at a scheduled appointment or by telephone. At this time, the physiotherapist ascertained the potential participants interest in taking part in the study. For those who agreed, names and telephone numbers were released to me and permission for me to contact them was obtained by the physiotherapist. Subsequently, these nine participants were contacted by telephone. At that time, the study was briefly explained and a convenient interview schedule was arranged for the participant.

Ethical considerations

Permission to conduct this study was granted by the Human Investigation Committee of the Health Science Centre, Memorial University of Newfoundland following a review of the proposal (see Appendix B). Approval was also obtained from the ethics committees of the hospital involved and the Health Care Corporation of St. John's, Newfoundland.

A signed and witnessed consent form was obtained from each participant after a thorough explanation of the following information: purpose of the study, data collection procedures, approximate time required from the participant, and the ability to withdraw from the study at any time without suffering any repercussions. Permission to tape the interviews was also part of the consent. Verbal consent was obtained prior to note taking. Before signing the consent form, each participant was given the opportunity to read the consent form and ask questions (see Appendix C).

The participants were informed of measures which would be taken to assure their anonymity, such as the use of codes for identifying the tape recordings and transcriptions rather than the use of names. Each taped interview was erased after transcription and I secured the transcriptions in a locked cabinet. As well, participants were informed that their experiences would be described in a manner by which their identification would be impossible. To assure them of anonymity, a copy of the initial data analysis was made available to all participants.

There were no identified physical risks as a result of this study and none of the women demonstrated any evidence of being upset during the interview process. Participants were also informed that even though they might not benefit directly from the study, it was anticipated that the information could enhance nursing research. This information could also benefit all health-care consumers, especially those experiencing the phenomenon of living with FM.

Interview approach/data collection

The unstructured interviews were audiotaped and conducted at a time and place convenient for the participant. All but one interview was conducted in the participants' homes, while the other interview was conducted in my home. As indicated earlier, the study was fully explained prior to the beginning of the first interview. Since many persons who suffer from FM find it uncomfortable to sit for extended periods of time, each participant was invited to move around and stretch as she saw necessary. These measures were implemented in an effort to promote physical comfort.

Primarily, data were collected through one or two tape-recorded sessions which lasted approximately sixty to ninety minutes for each participant. Following these interviews, at two week and four week intervals, each participant was contacted by telephone either for the purpose of obtaining further information or for clarification and elaboration of existing information. This process allowed me to obtain a fuller description of the experience.

Interview technique

Data were collected by the use of unstructured interviews. This format elicited both definitive and broad statements from the participants as they provided information from personal experiences. At the beginning of the interview the participants were informed that I was interested in obtaining their thoughts and feelings, and any other information they might feel would be helpful in describing the experience of living with FM.

The participants were encouraged to describe their experiences as thoroughly as possible without interruption. At times I needed to redirect the participants to comments which required elaboration. In these situations I used prompts and reflective techniques, such as "you mentioned fatigue, would you like to elaborate a little more on that aspect of your life?" or "when you hear comments like that, how does that make you feel?" These techniques helped the participants to elaborate on areas that they had raised and were important to them. The session ended when the participant exhausted descriptions of the phenomenon, and new information did not emerge, or if the participant appeared tired. Additionally, throughout the interview I recorded observations regarding non-verbal communication cues, and interactions between a participant and her husband for the one interview where the husband was present.

Data analysis

Immediately following the interview each participant's taped interview was coded with a label, and transcribed verbatim. This process of self-transcribing the interviews, allowed me to become immersed in the data by listening to the participant's verbal descriptions. This step also allowed me to get a sense of the whole or to gain an impression of the context of the conversation. Re-listening aided me to pick up cues of "how" the participant was saying "what" was said. Reading and rereading the verbatim transcription as the corresponding tape was played ensured accuracy of the written description and aided me to come to a better understanding of each participant's experience. Following transcription, each participant was given a typed copy of the interview and asked for feedback. Each participant indicated that there was nothing new to add, however, some participants wished to clarify certain statements. Consequently, the transcriptions from the audiotapes were then reviewed for emerging themes.

van Manen (1990) described themes as "knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through meaningful wholes" (p. 90). For this research, the specific approach used to reveal the thematic aspects of living with FM was that of the selective or highlighting approach outlined by van Manen. In the selective highlighting approach used in this study, the text was read several times and specific statements which revealed something about the phenomenon were underlined or highlighted. Following this process, I took each of the highlighted phrases or sentences and attempted to capture them as clearly as possible. After the summary of themes was completed, participants were contacted concerning the emerging themes and asked if these themes reflected their true experiences. The intention was to ascertain the participants' perception of the data and to have them come to a consensus about the emerging themes. As a result of this exercise, some participants suggested minor changes in naming a theme in a particular manner, hence, most of the titles of the themes came from the participants' own words. This collaborative approach to data analysis was necessary to ensure that my interpretations were truly reflective of the lived experiences of the participants.

Following the initial readings and mutual identification of themes in each interview by the participants and myself, I met with my research supervisor to discuss these themes. During that meeting, themes which needed further examination and elaborations were identified. The other identified themes were refined and comparisons of themes from each interview were made.

After the interviews were fully analyzed and themes identified, I met with the research supervisor and one other member of the thesis committee. At that time I presented the identified themes and discussed why I had chosen these themes. The other committee member could not be present, however, he was provided with a copy of the transcribed interviews and subsequent emerging themes. This process of collaboration further aided me in understanding the participants' experiences of living with FM. Participants were once again randomly selected and called to ascertain whether or not any new information was available. No new themes were identified as a result of these calls, however, conversations with the participants helped me describe and understand the preliminary themes in more detail.

Thematic statements that emerged from this process were used in developing the text used to describe the meaning and significance of the participants' experiences of living with FM. Each theme was written several times and discussed with my thesis supervisor until the phenomenon under study was described as accurately as possible. Finally, the essence, or that which gave a true meaning to the lived experience was captured and described in text.

Credibility

Credibility, in human science research, measures how well and true the descriptors of the phenomenon are performed, and should not be evaluated against the same criteria as quantitative research (Beck, 1994; Sandelowski, 1986). A qualitative research study is credible when the people having the experience being studied immediately recognize it as their own (van Manen, 1990).

To ensure credibility of this research study, the following measures were used: (1) the research study was supervised by two faculty members proficient in phenomenological methodology, and by a rheumatologist who acted as the content specialist; (2) themes were discussed with faculty members and analyzed according to van Manen's highlighting or selective approach; (3) I returned to the participants and confirmed the essence or hidden messages. Affirmative statements such as "it seemed like everything was written about me", "I couldn't tell what I had said from others' statements", "this was unreal, I felt like my life was on paper in front of me", and "thank you for telling it like it is" indicated that the participants believed the descriptions; (4) my interview technique was closely monitored by the research supervisor to determine if areas required further exploration; and (5) all participants who shared their experiences of living with the condition had a definite diagnosis of primary FM.

In addition to the latter measures to ensure credibility, I consciously attempted to control any bias by recording personal perspectives about the condition before, and during data collection. Frequent consultation with the thesis supervisor and other committee members also served to keep me focused and mindful of the research question.

CHAPTER 4: FINDINGS

The findings are divided into three sections. Section one is a brief description of the participants' characteristics; section two is a presentation of the themes with descriptive and interpretative material; and section three is the interrelationships among the themes, along with the essence of the lived experience.

Participants' Characteristics

Although the women in this study have many similar characteristics including martial status, diagnosis, and nationality, there was a fair amount of diversity as to personality and specific defining characteristics such as social involvement, mental capacities, values, life style, and health status. The combination of these similar and unique features allows me to capture the rich diversity of experiences applicable to this study.

Nine women ranging in ages from twenty-nine to fifty-six years participated in this study. Just as their age varies, so does the duration of their experiences of living with FM. Some had been diagnosed just over a year at the time of the interview, while others had their diagnosis for three to five years. Still others suggested that they had been dealing with FM since they were adolescents or young adults. A number of participants related stories about "the revolving door syndrome" since they were referred to numerous specialists and had various evasive and non-evasive medical procedures performed in attempts to get a diagnosis. Two participants said that they could not remember a time when FM was not a part of their lives.

Seven of the participants are married and live with their husband. While some participants have young children living at home, others have children who have moved away from the family home. The ages of the children vary from two years to adulthood. Of the two single participants, one has two young children, and the other woman's children are grown and have moved away.

The educational level of the participants range from completion of high school to completion of a postsecondary education degree. As such, the occupations of these participants vary and entail areas such as the service and financial sector, business administration, secretarial, and health care provider positions. Some of these women are no longer employed outside the home, while several of those who are employed have reduced their hours of work to part-time.

Thematic Analysis

The following thematic analysis provides a more complete picture of what these women faced daily as they confronted their illness. Their stories which provided the themes for analysis had unique aspects, yet many components were interrelated. Each experience was not viewed as a story about an illness, but instead, as a descriptive account about baffling symptomatologies of the chronic condition of FM.

For the most part, the experiences of living with FM were filtered through the descriptions and interpretations of the main symptomatology. However, some themes also emerged which were not part of the symptoms being experienced, but were wider implications of living with FM. These themes assisted me to move toward a richer understanding of the experience of living with the symptomatology of FM. The order of presentation should not be considered to have special significance since all themes have equal importance in capturing the phenomenon under study.

Pain: The constant presence

Pain, as a constant presence, was a prominent theme throughout the interviews. All the participants in the study described the constant nature of their pain. Webster (1982) defined constant as "faithful, fixed, firm, not changing, remaining steady in nature, persistent, or going on all the time" (p.390). Participants stated:

> I was crazy with pain all the time, absolutely crazy. It never stopped. I've not had five minutes of being comfortable since the accident.

> Today I am aching all over with no one spot been any worst than another. I am aching from the top of my head to the soles of my feet. Even on a good day there is pain. There is never a day when I am pain free, never, there is always some pain somewhere.

> You have to understand the pain is always there, there is always pain somewhere, not always as severe but always there . . . painful areas are always developing somewhere. It seems as if I have pain somewhere almost all the time.

For the participants who rarely experienced a day without some degree of pain, and for those who experienced pain every day, the real challenge was in determining how to cope with the constant pain and regaining a measure of control over something that was very subjective with few objective signs. Participants stated:

> Just look at me. Can you see any aches or pains? My God, I look wonderful don't I? So how can you believe me when I say this whole body hurts all over, all the time.

> You know all these repetitive movements that everyone takes for granted, like reaching, and which before this [FM] I did automatically, will now, my God when I reach I can feel the tightness and stiffness in my arms and back. All these things are considered chores. Just setting here reaching across the table reading the newspaper is a monumental task for me. Reading a paper is not supposed to be a difficult job so if I say "my God, I was in some pain when I was reading the paper", how can I expect anyone to believe or understand what I'm talking about?

The acute pain was a protective mechanism for the women which helped them monitor their activities. However, for some women in this study chronic pain also had a protective mechanism. One participant related that on a good day, that was a day when she felt less than usual pain, she would tackle household chores that she had deferred indefinitely. It was during these situations, as her pain increased, she acknowledged her heightening pain sensation as a warning to 'back off'. Thus, pain was telling her to rest and not to overextend herself. Pain for this participant acted as a meter by which she measured her ability or inability to perform daily activities.

Others did not consider pain in such a positive light and viewed pain as serving no useful function since it caused untold misery and suffering, and limited their ability to function adequately. They associated their pain with enormous physical, psychosocial and economic distress, and its ever constant presence exerted a negative influence over these women's lives. Thus, chronic pain, with its continuous presence, steady in nature became overwhelming as it demanded constant attention and interfered with normal activities of living, activities that were once considered routine.

> Just getting halfway through tasks is now a reality. Trying to sweep the floor is impossible. Not being able to complete tasks that I had planned to do is very upsetting. Generally I can't finish them because of the pain. This pain can be anything from a dull ache to extreme.

All participants related stories of their perceptions of how members of the health care teams negatively stereotyped them as individuals with chronic pain. This negative stereotyping contributed to the discounting of their complaints of pain. This lack of validity, by the health care team members and significant others, only served to compound their frustration and anguish.

> I find that there is a constant battle for me and my condition to be validated. I constantly have to repeat my symptoms [pain], to him [doctor] so he'll take me seriously.

All the participants felt that many professionals did not give credence to their pain experiences since there was no identifiable pathology. One participant summed up these feeling when she stated "if I had crippling arthritis or something disfiguring, things would be different." Another stated:

> Because the pain is something they can't see, I don't feel it is legitimate. I feel like I am always making excuses. I feel that my whole life is an excuse now.

> Pain is very personal, no one can see it or feel it. The medical profession, not all of them but some, believes that if it doesn't show up on an x-ray or blood test or MRI, then it is not real or not there. But that's not the case. I told one [doctor] that I wished I had a meter to measure my pain and discomfort by. Some of them look at you as if you are crazy, or look at you as if you are looking for something to be wrong so you don't have to do things.

Affirmation of the negative influences of pain was related by the participants. These negative feelings were evident as the participants described the variation in the severity of the painful experience.

> There's crazy signals going through your body. Everything hurts, everything feels like, they say, "a truck ran over you". I feel like my body has gone through a major physical exertion, like major exercising, running a marathon . . . . I feel like I've abused my body.

> I feel like I've been beaten, that's how I feel, like someone has taken me, shaken and twisted me and everything hurts . . . that's how I describe my pain.

Trying to be productive on the job despite the pain was a reality for several participants. Many related concerns about this painful intrusion and worried how it would affect their ability to maintain their jobs. Fear of losing their job based on less than standard performance was very real. One participant stated:

> When I feel the pain in my hands and thumbs, I know I won't be able to hold a pencil, therefore, if I can't hold a pencil, then there's not a lot I can do for that day. I know that I'm not going to manage well that day.

Despite the variation in the pain severity, there was an underlying relative uniformity in the pain pattern. The pain was usually diffuse and widespread, and tended to be axial in location especially involving the neck, shoulders, back, pelvic girdle, buttocks and upper thighs.

> It could be anything from an ache in my shoulder or an ache in my ankle to being a severe pain anywhere in between. Those pains may come and go quickly or they may stay all day.

Some participants had difficultly accurately describing the location of the pain and were likely to say that "I hurt all over." Several participants related that for them "there was never a day without pain." However, some noted that occasionally the pain was intermittent. Other words which were used to describe the constant presence of pain were "burning," "gnawing"' "shooting"' "dull"' and "spasms." The pain's actual location and degree of severity varied from day to day, and in some cases from hour to hour, and this caused much frustration.

> Yes, and it happens in muscles that normally wouldn't be affected like the back of my ears, my jaws, my whole neck area, the pads of my hands, and the soles of my feet, and also my shoulders.

> Another problem that I am experiencing is eye pain. My eyes pain something terrible. I can't attribute it to any one thing. It could occur when I am trying to read or sew, or for no reason.

On some days, there was little pain and mild discomfort. During these times, rare as they seemed to be, the women were able to move around freely and participated in usual family and social routines.

> On a particular good day [with little pain], after I shower, I'll make sure the house is tidy, probably I'll pick up a few groceries, drop in on a friend for a cup of tea, and then be able to have supper on the table for my husband.

> On a good day, I won't be too stiff and sore. I can get going then, and do a bit of housework, and act normally.

The next day, or even for some participants the next hour, the amount of uncontrollable diffuse pain made doing anything impossible. Pain with its limitations caused tempers to flare and increased feelings of helplessness.

> Some days when I'm so bad, the pain becomes so intense. It starts in my jaw and travels down to my heels. It's the most horrible, sharp pointed pain. It makes me like a savage. I'm not fit to live with anymore!

> There've been days when I've gotten to work and yet have not remembered how I got there; partly because of some medication and partly because everything hurts so much at the time. Focusing on the pain, everything else just takes a back seat.

Pain with its diversity of location and severity was difficult to control. Often pain killers were ineffective, and what worked one day was useless another day. Being unable to control this aspect of FM left these women feeling helpless and not in control of their lives. Pain, with its constant presence, assumed more importance in each woman's life as she felt out of control.

> On a bad day when I awake, I'm so stiff and sore, full of aches and pains. I'd just as soon get on the chesterfield and stay there all day.

Touching, which satisfied the need to feel and make contact with another human being, takes the form of caressing, cuddling, holding or stroking with the fingers or whole hand. For many participants this was a dreaded activity because most days they experienced total body pain, and any form of physical contact accelerated pain sensations. This factor caused them to avoid areas where large numbers of people meet, like shopping malls and elevators, where there was the possibility of being accidentally bumped or touched by another person. One participant stated:

> My body hurts all over, all the time. I'm afraid someone is going to squeeze me or bump into me or that I'm going to bump into something.

Another participant described how she cringed when her robust son gave her a hug because no matter how gentle he was, the embrace was always painful. She longed for this expression of love and caring, yet she was fearful of the pain she knew she would experience. Another participant explained how painful her skin was when she was examined by her doctor.

> When he touched my back in a specific area, I nearly flew across the room. There are times now when I don't want my husband to press hard when he is putting cream on my back.

Most participants needed to undergo a profound change in their usual daily activities as they confronted their pain. These activities, which included being wife, mother, grandmother, friend, lover, employee, and so on, were gradually eroded. As well, most participants related stories which spoke about an inability to carry out routine household tasks. These tasks were associated with the homemaker role, a role which they no longer enacted. Stories related by the participants included:

> Just pushing my son's little stroller, that was something to do. I couldn't even push it. Just pushing this little stroller, I'd be constantly complaining to my husband. I was having all those aches and pains.

> Last spring I had a man and woman come in to clean and paint for two weeks. Can you imagine how I felt having to get someone to do that when I always did it and enjoyed it?

> All my aches and pains were blamed on that [low estrogen level]. At that time my husband felt that I had lost all interest in him and our little son. I was in so much

> pain all the time, so miserable, so drained, and it seemed as if no one was believing me.

The participants often felt that many of their families, friends and health care professionals saw them as malingers since they did not understand the extent of their pain. One participant stated "I looked so good, yet I feel so rotten. This makes me feel like a fraud."

Several of the participants believed that the presence of constant pain placed undue stress on martial relationships. One participant believed that her constant pain was a contributing factor in the breakup of her marriage.

> After this [FM] and I was in so much pain and misery, so withdrawn compared with what I was like before, well it affected or took its toll on our marriage, and I just didn't care. In the beginning, and even after I couldn't do anything anyway [engage in sexual activity] because of the pain.

> This [pain] causes relationship problems. I'm so cranky, I'm in so much pain that all I want to do is pound my fist through the wall.

Fatigue: The invisible foe

Fatigue was another defining feature of the experience of living with FM. All participants described episodes of fatigue as being insidious, a feeling that crept upon them unannounced and without warning. This feeling could occur at any time of the day or night, exhibiting the same ominous characteristics of an enemy or a foe. While no one knows why fatigue is such a prominent characteristic symptom of FM, it is, and the participants in this study had many adverse consequences as a result of fatigue. Fatigue had drastically reduced the positive quality of the life for all participants in regard to employment and social activities. Hence, fatigue was a very debilitating feature of FM as it interfered with essentially every aspect of their lives.

Webster (1982) described a foe as "an enemy, one who harms or restricts" (p. 710). All the participants described fatigue in similar language or terms. Several participants described their fatigue as "the ghastly sensation of being totally drained of every fibre of energy." They had a prevailing feeling or premonition that if they did not sit or lie down, then they were in immediate danger of collapsing. Many participants rated the fatigue component of FM as a greater disability than any of the other symptoms since there was nothing they could do to prevent it. For these women, the fatigue experienced was not the kind which resulted from busy daily activities. This fatigue did not disappear after a good night's sleep but engulfed the person with an overwhelming sense of total exhaustion.

> I get so tired, so drained out when I do anything even for half an hour. My whole body feels completely drained of energy; not the tired feeling from being sleepy, but a totally exhausted, drained feeling . . . just like you're going to drop down.

Fatigue, as a prominent feature of FM, was a major factor limiting many participant's ability to do routine tasks. Others stated that fatigue made it much more difficult to do anything extra.

> I've gone from working 10 to 12 hours a day, and doing all the house work after I came home from work, and still had energy to go out in the evening. From that to now, with just about any little thing exhausting me.

The fatigue described in these narratives was not the type of fatigue most people referred to as they saw themselves as "being tired" after a day's work or some other form of intense activity. These participants described a fatigue which severely hampered the quality of their lives. The effects or symptoms of fatigue for these women were evident in some lifestyle changes necessitated by the overwhelming presence of fatigue. As one participant stated:

> I have to push myself for everything. Everything is push, push, push. Sometimes it seems like there is no energy left to push anymore.

Fatigue, for the most part, was precipitated by usual activities entailed in performing everyday activities. A participant explained:

> Fatigue is very much a part of this condition for me. The littlest things exhaust me. Just helping to prepare dinner or helping to clear away, I get totally exhausted, totally wiped out.

The expenditure of any energy for these activities resulted in undue fatigue. For many, social and leisure activities had to be canceled. A participant stated:

> You have to give up things because it's so hard on you now to continue with old habits - you don't have it [energy]. I loved company, I loved having people in, having parties and dinners. Now just the thought of it, makes me think twice, am I up to it. Life [social] for me has changed drastically.

Hence, a general lack of energy and feelings of unsurmountable fatigue often dictated that certain activities and tasks had to be avoided. Activities and tasks had to be prioritized to permit expenditure of precious and limited energy on more valued activities. For most of these women planning ahead for the short term had become a way of life, and not necessarily the way they would have chosen if they had the option of other choices.

> If I am going out now in the evening I have to make sure that by 1 or 2 p.m. I have my bath. If I leave it for later in the day, I know I am not going to get there because I know I can't rush for anything. If I do, I become totally exhausted and then I'd have to lie down.

The narratives substantiated that symptoms of fatigue dictated the performances of most or all activities normally undertaken in daily living.

> I went for a walk today, I did it because I thought I should. There's not supposed to be a reason theoretically that I can't do it, except that I don't have the energy. It seems to take more and more energy for every step, more than I've got to put into it.

Since the presence and level of fatigue fluctuated, the degree of the severity was certainly the standard by which all physical activity was measured. What was manageable one day, was impossible the next. One participant wondered "how come one day you can leap over high fences, and the next day you can't pick up the vacuum cleaner and do the family room? Often tasks which were considered routine, and were hardly given a second thought, now were considered in a different light. Extra time and energy were required to accomplish the tasks at hand. One participant stated, "even lifting the kettle off the stove is very difficult. Who in their right mind can believe that?" Another stated:

> I do just about everything there is to be done around the house, it's just that now I am more reluctant to do it. I don't feel that I have that much energy to spend.

When both fatigue and pain were present, all participants reported incidents of increased dependency on other family members. Others reported limited physical endurance since they became tired more quickly. For many, after a day's work outside the home, there was little energy left for the family or family related activities. Feelings of fatigue caused a wife and mother to feel guilty as she saw her husband attempting to prepare supper after he arrived home from a busy day at work.

> I have hectic schedules and deadlines at work. Then sometimes when I come home, if the kids are tired and upset, they might get on my nerves more easily. To make the day worse is when my husband is also tired, he's had a hard day, he's worked all day too.

Fatigue and its consequences also meant that participants relinquished some of the roles which they normally held. This meant changing old habits and routines, and negotiating new ones. These changes were not made without a sense of loss of ownership. All participants shared stories of relinquishing home-maker roles, some parenting roles, wife roles, social roles and employment. As with all other interventions which were necessary to manage living with FM, adapting to or accepting changing roles, was more difficult for some than others.

> I look around this house and see things that need to be done and I can't do it. I don't want always to be keeping on either. I can't do it and I don't expect my husband to do it either.

> I don't work the way I used to [at the job]. I always expected a lot from myself, especially in my job. I felt I was very good at what I did and I expected to

> continue being good. I'm not as good as I was before and that is a major struggle for me. I found this part of my life very difficult to handle.

Increasing dependency created a cyclic response of fear of abandonment and loss of independence, a sense of being a burden to others. They felt that they were always on the receiving end and not on the giving end. One participant echoed the feelings of others as she stated "you can't always be burdening your friends with your troubles and needs all the time." Another stated "because you can't do things like before, you make your friends uncomfortable. Therefore, you don't want to burden them by being in their company." Fatigue robbed and restricted the closeness of established relationships. Being too tired to take part in usual activities curtailed friendships for several of the participants.

> I love being with people but it doesn't seem to be enjoyable anymore. I feel so tired all the time. It seems that I have to spend so much energy even to have a conversation.

Another participant related:

> I don't see several of my old friends anymore. Actually, I feel they became tired of calling me when I wouldn't be able to do what they wanted me to do. Because I am so tired all the time, I am not the same person that they once knew.

Leisure activities, such as dancing or going to a movie, were modified or adapted by the participants and significant others. Instead of going out to a movie some participants rented a movie. The need to move around would be distracting and irritating to others in the theatre. Since many participants reported that they were sensitive to cigarette smoke and noise, they avoided visiting places where these activities occurred. However, fewer strenuous activities that required social contact were initiated. These activities included meeting friends for coffee or lunch, going for leisurely walks and often watching from the sidelines as their children participated in swimming and hockey. Others reported enjoyment from reading and listening to tapes.

The overwhelming nature of fatigue was described by some of the participants as devastating as a flash-fire, it was all consuming. When the foe, fatigue, reared its ugly head, all other aspects of life were altered or compromised. For many participants the symptom of fatigue was often closely associated with pain. Many believed that the overwhelming feeling of exhaustion occurred as a direct result of using extra energy to do the very simple tasks because of the constant presence of pain. One participant stated "believe me, it takes every bit of energy and effort I have to keep going [after I get home from work]." Others stated:

> I get up in the morning now, and feel as if I was on a cold boat all night. I feel so tired. I slough my way to the bathroom, and then I slough myself to the kitchen and sit at the table and wonder if I have enough energy to get a cup of tea.

> Even when I have done my bit of work in the morning, dishes and tidying up, and then do my exercises, I really do need to lie down again. There is no energy left for anything else.

Fatigue caused conflict in other husband-wife relationships, and one participant anguished about the negative effect fatigue had on her marriage.

> Fatigue causes relationship problems because I become so cranky. I'd be the first to say I'm so cranky when I'm tired, I don't know what is wrong with me. I wasn't normally so irritable.

From the narratives it was easy to understand that the amount of fatigue differed from one participant to another. Since the symptoms changed so frequently, all participants had concerns about running the risk of overextending the physical boundaries imposed by FM, which resulted in their becoming over fatigued. This was especially true for women who were successfully employed outside of the home before they had FM. Their careers were exciting and challenging, both physically and mentally, and thinking about fatigue was never an issue. But now, the reality of becoming overtired and exhausted was attached to every activity they undertake. A participant stated:

> If I go to the mall or supermarket and walk around for 20 or 30 minutes I begin to feel like "Oh my God, I'm gone again". I have to look for a place to sit down or go home. Before this [FM], I could spend 24 hours in the mall without a hitch.

> My God, I could jump over the moon, now I can't even shop in pleasure. Nothing is pleasurable anymore because I am so tired all the time, and seem to lack so much energy.

Sleep: The impossible dream

Each participant identified sleeplessness as having a major impact upon their lives. According to Roget (1990) all words associated with sleep are restful and quiet, denoting a sense of inactivity or inertness or motionless, a time of restfulness. For all these participants their descriptions of sleep were anything but restful. Sleep was different for each person, however, most experienced many of the same sleep characteristics and rituals of preparing for, and going to sleep. Despite the use of proven non-medical sleep remedies such as taking a warm bath, eliminating caffeine early in the afternoon, and reading a good book, many of the women described their inability to get a "good night's rest."

Two kinds of sleeplessness prevailed throughout the narratives. Initial insomnia occurred when a person went to bed and could not fall asleep, whereas terminal insomnia occurred when the person fell asleep quickly but awoke after only a few hours of sleep, and could not resume sleeping. The participants experienced both types of insomnia and the end results were the same. Their perceptions were altered, reaction time became slower, efficiency, judgement, attentiveness and the ability to complete tasks were diminished.

> Falling asleep is a major problem. I can go to bed at 10:30 p.m. and still be awake at 3 a.m.

> Staying asleep is next too impossible. I'm never truly asleep. I'm like I'm in the twilight zone, aware of everything, can't get pass it.

Some participants reported that they appeared to sleep through the night, but upon awakening felt unrefreshed and as tired as they were upon retiring for the night. Several participants reported wandering around the house, becoming more and more frustrated as morning approached, and knowing all too well the end result of a sleepless night.

> Sleep, or lack of it, is the worst thing about this condition for me. I have christened my bedroom "the torture chamber." Most nights it's like playing musical beds! I'll end up sitting on the edge of the bed, trying to relax, deep breathing, trying anything to make myself sleepy!

Many of the participants believed that the sleep disorder was caused by their experiences of chronic pain. Some wondered if the stress they were experiencing due to FM had them in the downward spiral effect of a stress-sleep related disorder. One participant stated:

> Sometimes I get into a cycle of not sleeping. Then everything [symptoms] gets worse and worse, and it becomes some real crisis. I'm never really rested when I

> get up, I'm like I'm still aware of what is going on around me. It's like being in the twilight zone [when sleeping].

Several participants suggested that if they could get a 'good sleep' maybe the pain and fatigue would be lessened. However, most had resigned themselves to the fact that a good night's sleep was 'an impossible dream'. One participant indicated that probably three or four nights a week she seemed to sleep for the most part, through the night. However, her body and mind did not consider it a good quality sleep. Even on these mornings, upon awakening she felt as if she has just gone to bed. Others who related similar feelings, all agreed that it was very difficult to face a whole day when still experiencing exhaustion from the previous day. Life was very difficult when these periods of minimal sleep continued for months. In their descriptions of sleeplessness, many participants felt that this was another way in which their bodies continued to betray them. It was not working like it used to, or as it was supposed to work.

Thinking in a fog

Throughout the interviews, participants described difficulties with problem solving, including abstract thinking and making appropriate judgement calls or decisions. These cognitive losses were very difficult to accept. This was evident from examples given about memory loss, forgetfulness, confusion and sometimes disorientation.

> Another serious challenge for me is the loss, a major loss, of my cognitive abilities. My mental state has really changed. FM has altered my brain, . . . it feels like it is wrapped in cotton wool.

> I find that my memory is really bad, and if I'm really tired I just can't figure things out. My head feels light-headed a lot. It seems to take a lot more attention to concentrate.

For these participants, it seemed as if their body and mind were constantly on a battle field, unable to work together and to harmonize for a meaningful existence. Most participants described the problems with their cognitive abilities as being scary and frightening since they had not discovered any measure or intervention to help them cope with these problems. For pain, there was pain medication and other types of relief, for fatigue resting helped for a while, but for cognitive difficulties there were no solutions. Many described feeling as if they had fallen through a deep dark chasm. There were no lights, no distinguishable sounds, only darkness and the feeling of falling, falling. The war continued, the body and mind were not connecting.

> Before I was diagnosed with FM, since that process took awhile, it was though suddenly my body wasn't mine anymore. It was as though my body and my mind worked independently of each other. My mind wanted to do one thing, but my body couldn't.

Actions became confused and motor abilities were spastic. In a normal conversation words were heard but they had no meaning. These difficulties made it impossible for one participant, a university student, to attend regular classes. She was fulfilling her degree requirements by means of correspondence studies. Although she needed longer time to complete her degree, this method was the only way she could cope with, and absorb the required material. Another participant who held a challenging executive position prior to her diagnosis stated:

> FM takes away my ability to concentrate and remember. Sometimes I know what it is I want to say, but I can't seem to find it. When I think about what I used to do, and what I had to remember and be responsible for, I really don't think I could do it today because I can't concentrate long enough. My mind just seems foggy all the time.

Memory lapses often lasted for hours, weeks or months. Dealing with short term memory lapses was most difficult for all participants. They constantly misplaced grocery lists and left milk cartons filled with milk on the laundry room shelf. One participant recalled how embarrassed she was when she could not call her best friend by name. She also recalled another situation where she experienced profound panic because she did not remember where she had parked her car on a shopping mall lot.

> I've come out of the mall and have literally forgotten where my car is parked. I can't find my car! Now I might come through the right door, but I still couldn't

> find my car, might know what direction, but not be able to find the car. Now that is frightening.

It had become constantly necessary to make lists. This was described by a participant who worked in a secretarial position. Recently, she had become very forgetful which was something she could not allow to happen in her job. Even when she made lists and placed in prominent places, she often forgot to look at them. Another participant recalled how scared she became when her short term memory failed her. One day while she was walking down her hallway she forgot where she was, nothing looked familiar, and momentarily she felt lost and alone. Almost in a panic state by now, she remembered it was her home, but why she was in the hallway still eluded her.

This feeling of being disconnected to time and place can happen to anyone. This fact was acknowledged by all participants, however, they felt that these occurrences of body/mind disconnection happened more often to them because of FM. Many recalled embarrassing situations when the next word in a sentence would not come out. One participant related:

> What should have been a very simple sentence now becomes a snarled group of words without any meaning for others, however, to you it makes sense. The very word that you have been groping for makes you stutter and stammer, it might be a simple word like "the," and not an unfamiliar word or object.

The body/mind disconnection often caused physical discomfort. This was evident as one participant described a situation where she forgot to implement activities that she would normally do to minimize her physical discomfort. This happened on a day when she felt less pain and fatigue when she briefly forgot the need for pacing activities. She overstepped the boundaries of her limitations and was confined to bed for several days. For many participants, the loss of former cognitive abilities was more difficult to accept than the physical limitations imposed by FM. Some participants revealed that this "fuzziness of the brain" had a deleterious effect on their ability to be gainfully employed.

> My job is one of an analytical position. I don't work the same way as I did before. I'm not as good as I was before, and that is a major struggle for me.

Another participant, who kept a journal while on a trip, revealed that she constantly referred to notes to remember where she had been the day before. The calibre of her writing had changed, her sentences ran together and she had difficultly reading the notations. This was a shocking revelation to her and immediately she figured she had the symptoms of Alzheimer's disease, especially since her father had developed this condition.

Several of the participants, who prior to being diagnosed with FM loved to read for pleasure, now found it difficult to concentrate long enough to get enjoyment from reading. Others found it difficult to focus their eyes.

> I'm not able to read as I like to and I find it harder to read. That really frustrates me. I used to read a lot, but not anymore. Besides the problem with concentration I have trouble with my eyes.

> Another frustration is my inability to read for any length of time. I used to love to read. I read everything I could get my hands on. Now it takes so much effort to read.

Dealing with a flare-up

Dealing with a flare-up was a major theme addressed throughout the interviews. In FM, unpredictability of symptoms was part of living with the illness, especially since the symptoms were of such a fluctuating nature. A primary concern for all these participants was to control the physical and mental attacks. This was especially true concerning which symptom would flare-up, the areas of involvement, the length of time the flare-up would last, and symptom severity.

Some participants voluntarily restricted their lives because of the unpredictability of symptoms. Many suffered from disruptions in their lives that went beyond physical discomfort; many individuals were reluctant to make long-term plans. Unpredictability of flare-ups made it necessary for some to relinquish their jobs, limit social engagements and avoid activity. The participants hoped that these actions would bring some stability to their condition. However, for some this hope was dashed as the loss of a job curtailed other social activities generating fear of social isolation.

> Not being able to go to work was the worst result of this condition for me. Most of my social life was intertwined with my job, therefore that was also taken from me.

When symptoms became aggravated by some unusual stress or activity, participants felt as if every cell in their body was screaming, all at the same time, for relief and attention. Some participants described how a "flare-up" of symptoms disrupted their lives. This flare-up could be caused by something very simple, like a change in temperature or weather, or something more serious like a viral infection or a family crisis. During these flare-ups, participants described the exaggeration of minor older symptoms and the experience of having to deal with newer ones. These new symptoms ranged in severity from a mild rash to the inability to walk, or take care of personal needs.

During a flare-up all participant described a decrease in muscular strength and some difficulty in walking. One participant described her pattern of walking as "the FM shuffle." Others related stories of brief disorientation and frightening situations which included bumping into objects, experiencing difficultly pouring liquids without spillage, and judging distances or sizes. Another participant stated "If you have cognitive problems before, when you are experiencing a flare-up, these problems are really greater."

In spite of the unpredictability of the flare-ups, others managed to maintain their jobs and felt a sense of satisfaction that their income contributed to putting the 'cream on the cake' and allowed for the extras that would not be possible for a family on one income. Some participants indicated that the unpredictability of the flare-up meant that it was necessary to receive adequate rest prior to going to work. For these persons, in order to function at work, all spare time was spent resting and sleeping. In the words of one participant:

> My life right now seems to centre around sleep and work, sleep and work. If I'm going to work, then that's how it has to be. That's exactly what I have to do.

Longing for a normal life

Generally speaking, persons suffering from a chronic illness or disability make a conscious effort to convey to others that their lives and that of their families are no different from other families not dealing with a chronic illness (Knafe & Deatrick, 1986). So it was with these women who were suffering from FM. Their common goal was a desire for a normal life and the ability to do things for themselves and their families even if it required a struggle. Despite the intensity of the pain and the reduced ability to maintain normal daily activities, each participant demonstrated ways in which they attempted to normalize or to convey to others that their family life was really no different. All participants related the importance of "doing family things" and of "keeping up a good front." Those attempts at normalizing were often achieved at great physical and emotional expense to the participant. However, all participants felt these expenses were a small price to pay for being seen as a person rather than a disease.

> I don't know, it's just that when you hear about someone with a particular disease or condition, it's like they're not the same person anymore or something. Somehow they're just changed, or people change the person with the disease to

> suit how they see the condition. People feel different toward you, they treat you differently and act differently when they are around you. They think you're not the same person anymore. I don't want that, you know.

Many participants believed that concealing the illness was necessary to avoid being stigmatized or treated differently. To maintain this illusion of normality some of the participants related how it was necessary to "cover up" or to "keep it from others".

> I don't let on to anyone just how badly I feel except to my husband. I don't want anybody to know. We always have company, and you know with company I waste so much energy to hide this [FM] from them.

> I get in the most trouble when I am in a frenzy of activity trying not to go over, yet trying to be normal. Nobody wants to be labeled disabled or different.

Even though participants disclosed how supportive and valuable friends were to them, some felt it difficult to reveal the real nature of their problem to those friends. One participant stated:

> Our friends know there's something wrong with me, but I never really talk about it to them. I still try to keep my diagnosis to myself.

For married participants, and especially those with young children, the desire to do normal things was critical to the functioning of the family unit, although the act of maintaining normality was often an energy draining experience. One young mother related that after returning home from a day at the office she was exhausted, but because of the immediate needs of her two young children, she had to keep going and do things that were important for her children. She stated, "believe me, it takes every bit of energy and effort I have to keep going, but doing normal family things is important to me." Another related:

> I have two small children, and I don't want them to say when they're older, we couldn't do this or that because my mom was sick. They're entitled to better than that. So as far as I can possibly do it, we live a normal life and do normal family things.

For these women, engaging in normal activities of daily living, fostered a sense of self worth and allowed them the joy of feeling and living a "normal" life.

The power of naming - seeking a diagnosis

For many participants, numerous visits and consultations to specialists and other practitioners resulted in a diligent quest for a diagnosis. These visits often added to the confusion and chaos. Often inappropriate treatments were prescribed. In one case, a participant was placed on a cardiac regimen, prescribed cardiac and asthma treating medication. As well, she underwent an angiography procedure. This incident and others simply resulted in the erosion of their trust in the physician and compounded their feelings of uncertainty. The complexity of symptoms that the participants experienced, coupled with the poor understanding of the syndrome by many of the physicians they came in contact with, made it difficult to obtain a proper diagnosis. None of the individuals could tell me about their experience of living with FM without telling me about this aspect. There were long recountings of going from doctor to doctor undergoing a variety of diagnostic tests and procedures. As one participant stated:

> People with FM have to prove to the doctor that there is something wrong with them rather than the doctor saying "yes, based on this and this you have a problem".

> It was wonderful to find out what I was experiencing was really a condition and that it was not all in my mind. Every symptom that I read about in the literature, my God, I had it all. There it was on paper, so it couldn't be all in my head.

These women knew that there was something wrong with them and for many they lived with this knowledge for a long time. The missing piece that they couldn't figure out was **"what"** was wrong. Their experiences were not so different from other people who experience health problems because like most other people, they wanted to know what was wrong with them. Participants stated:

> I read through the little pamphlet [on FM] and thought "that's me". Anyway, when the specialist put a name on what I had, you cannot imagine or believe the

> relief I felt even though I didn't know what FM was, and even though she said "this is forever". She put a name on it, you know. Before this I thought I was going crazy, going absolutely out of my mind.

> My wish for anybody diagnosed with FM is for them to become informed, reach out to support groups, look at videos, etc. For me, seeing the video was like "the sun coming up for me," all the unexplained symptoms. I didn't know what was what before.

Many of the participants related that lack of trust and confidence in their physician resulted in high levels of another kind of uncertainty for them. Not knowing what to expect in terms of causes and consequences of symptoms made life difficult. Knowing as well that many of their primary health care providers were not familiar with the condition further compounded the feeling of not knowing.

> The society that I grew up in told me if there is something wrong with you physically or emotionally you go to your doctor, explain the problem and he figured out what was wrong and told you how to fix it. Now I have to educate my doctor. I look to my doctor and expect him to help treat my condition, but how can he treat me if he doesn't know.

Others related incidents which increased their uncertainty when the primary care physician, who could not find a reason for the complex symptomatology, dismissed them as being physically ill, but rather as needing psychological help. One participant stated that "I was really beginning to believe it was all in my mind." Another participant related:

> I wish I had been diagnosed earlier. I wish I would have been given a program to follow. When I was diagnosed I wasn't given any information.

Another expressed the view that being a woman in a predominantly male health care system, and having a condition that afflicted mostly women was another reason for the uncertainty that existed among women perpetuated by the physician.

> I think that women are generally looked down upon by the male medical profession. I don't think that with my disease women are treated, or are as well served, as their male counterparts. I have seen it happen. When a woman comes into the emergency department with chest pain, the doctor's [male] first reaction is that it is caused by hysteria or 'bad nerves', or someone is looking to get off work or it's an imaginary symptom, there's no such thing, etc. But if a man comes in with the same complaint, regardless of the age, all stops are pulled and the action begins.

Was there a clash between two forces here? A clash between the male dominated technical world of medicine and the view so often perpetuated by society that women are frail, emotional beings. Was FM seen mainly as a woman's issue since the negative attitudes of so many male practitioners were described.

> The doctor who diagnosed me was very negative. He just said, "if you get fit, get some exercise, you'd be fine." I felt it was like a pat on the head diagnosis. In other words, the problem with you is that you're too fat, and you are depressed. If you weren't depressed and fat you'd be just fine. This was very negative for my self image.

Many felt that the uncertainty they experienced in regards to not knowing what to expect was also affected by the way some of their physicians perceived the degree of severity they were experiencing. In this instance, the doctor felt there was something wrong, but felt that the degree of severity was really less than that being reported. This attitude by physicians, whom the participants respected and held in high esteem, caused them to be discouraged, depressed and often disenchanted with the health care they received. This message was evident in the context of the following statement, "I constantly have to repeat my symptoms to him so he'll take me seriously . . . I feel discounted a lot."

While each participant stressed the importance of being informed about FM for themselves and significant others, they also reiterated the value of education about the condition for their primary care physicians. For the most part, many of the participants were not informed about the condition by their primary care physician. Most obtained initial information from private sources, or later as they consulted a rheumatologist. This awareness of a lack of knowledge regarding FM by the primary care physician was a source of concern for many. As one participant stated "I look to my doctor and expect him to help treat my condition, but how can he treat me if he doesn't know how?"

Most expressed feelings similar to that captured by the participant who stated "hope keeps me going even though I don't know what is happening to me." When questioned about this statement, the general consensus was that hope made everything worthwhile. Hope assisted in protecting her against despair, and in preserving some resemblance of meaningfulness in her life. For others hope was the motivator which propelled them to carry on in spite of personal, physical, and cognitive limitations. Participants also described hope, not in absolute terms, but as something with an aura of uncertainty about it. The uncertainty of hope was related to the unknown nature of the outcome, or as one participant stated "hope and FM, you can never say anything with certainty."

These participants were used to living with uncertainty, therefore, the uncertainty associated with hope was not difficult to understand and accept. Many participants expressed a hope that a cure would be found or at least an effective treatment that would give them some small measure of comfort. As one participant poignantly stated: "all I hope for is a little comfort."

Most participant expressed hope that circumstances would improve or that remission would occur. Many hoped that the remission would mean that the condition had ended. For all participants this hope was dashed as they experienced a flare-up. Most participants related that maintaining hope helped them to produce the energy that allowed them to plan to some extent, to act and to stay involved in family activities, even if on a reduced level. Some participants were able to forge ahead and to look positively toward the future. FM was viewed as one obstacle that could be overcome.

Despite the controversies and difficulties involved in determining the diagnosis, all participants found an immense sense of relief in being given a name for what they were experiencing. Relief was evident as they realized their symptoms were not all imaginary. For many this information was the impetus to take control of FM. As one participant aptly described the situation:

> I know what I have. I know basically what can be done about it. Life goes on, and I have to move on with it.

Living within the boundaries

For the women in this study, this theme, living within the boundaries, was part of their daily life. For some, more than others, there was a realization that this acknowledgment was vital to their being in control of the condition, rather than have the condition control them. They reported that there came a time when they had to acknowledge that they were indeed living with a chronic illness that was different from anything they had ever known. The internalization of this information forced participants to make choices. The choices were to give up and let FM control their lives since so often they felt they were "running against the wind"' or to take control of the challenges presented by FM. Participants related poignant stories of attempts to rise to the challenge of controlling FM and not letting FM control them.

> Now I never know what to take on, how much is enough, how much is too much, what are the boundaries? I do know that if I over do it, I pay big for it. I have to

> find out how much I can do. What are my boundaries? If I can walk one kilometre and feel good, should I try to walk two?"

> You must remember that self-pity is your worst enemy. The worse, it will make you ten times worse. I am determined that's [self-pity] not going to happen to me.

By accepting the challenge to control FM by living within the boundaries, precious energy was no longer used to mourn losses, but rather, channeled into positive activities which made it easier to live with FM. Acknowledging the physical, cognitive, and social limitations allowed each participant to make adjustments as they learned to adapt to a different way of life. This did not imply, however, that while participants were learning to live within the boundaries that they did so without mourning losses which they had experienced. For all these women, losses had varying consequences. One participant revealed that her family and friends unknowingly disallowed her to mourn her losses.

> I had to learn that the body I have now is not the body I had before. I mourn for the loss of my life as I knew it. However, recognizing that you are going through this mourning period is normal. Even though you know it is normal you have a lot of guilt when people inadvertently make you feel guilty for mourning your losses and for feeling sorry for yourself.

These well meaning family and friends insisted that since FM was neither life threatening nor caused disfigurement, the extent of her mourning was out of proportion to the loss being experienced. Losses related to ill health, but which do not include death, tend to be minimized by others (Locke, 1994). It was somewhat difficult for others to acknowledge the extent of the emotional, psychological, physical, and financial losses which were due to ill health. These women all experienced similar losses, yet for each, invisible losses were personally defined and for the most part not openly discussed. Many of the women felt as this participant did.

> They'll ask how are you feeling, but you learn very quickly they really don't want to know how you are feeling. Sometimes people won't allow you to verbalize how you feel, they don't understand your needs for this, your need for time.

Most participants questioned their personal values since they relinquished many of their roles. There was a loss of "selfness" since who we are, is often defined by the roles we play. Some of the women, however, realized that living within the boundaries meant that this was how life would be for them from now on.

All participants related stories of personal growth as they learned to live with FM. Now they viewed their lives as if they were looking through a magnifying glass, and important choices were easier to make since they were easier to see. A renewed sense of inner strength and character permeated the stories as each participant related experiences of how they "lived within new boundaries." Each participant had become vigilant about feelings of fatigue and pain, now they were aware of when to take proper actions to alleviate or to modify symptoms. Knowing the condition by living within the boundaries gave participants control over their lives.

> When I get home [from work] I have nothing left [energy]. I have to rest, take time for myself and rebuild, not only my energy, but also my attitude.

> I've learned through a lot of frustration, a lot of self honesty, a lot of self-analysis and through talking with others about it [FM] and by reading. I may never control it, but I can have more control over what I allow it to do to me. I know now I can be more in control of this, more than some people give me credit.

Knowing the patterns and limitations of FM meant that participants' experiences of daily living were filled with the persistent and unpredictability of the associated conditions of FM. These conditions included pain, fatigue, stiffness, sensitivity to heat, cold, perfumes, smoke, noise, mood swings, bowel and bladder problems, usual problems, headaches, tingling in hands and feet, physical and cognitive deficiencies. In spite of all these difficulties, one participant acknowledged that since FM was going to be with her for a long time she must become friendly with the condition, and learn to live with it, despite its disadvantages.

> It's no sense in being angry, I must accept the fact that I have to make these changes, accept it - the anger goes away then and it's easier to accomplish whatever it is you have to do. Now instead of being angry, you use this energy to plan how you are going to do [what you want to do]. Therefore, you make it easier by accepting it.

Each participant related that knowing the limitations was pivotal to managing day by day life with FM. Acceptance of the limitations imposed by the condition was very difficult for one participant. She realized this characteristic within herself and wondered whether or not it impeded her ability to move on.

> My biggest frustration with all this besides the constant pain, the fatigue, the sleep disorder and all the other associated conditions is my ability to accept what has happened to me. I truly have not accepted what has happened to me. I know that to truly accept this will take forever for me, forever.

Living within the boundaries meant that to manage FM and to live a life that was meaningful, all participants had to rearrange or reschedule specific daily activities. Participant related stories about how it was necessary to be organized so that specific times throughout the day were scheduled for rest and relaxation. Other family members absorbed the more difficult physical tasks, such as vacuuming and laundry. Living within the boundaries meant that no matter which activity they undertook, it was vital to pace activities. The time dimension had changed dramatically. The pace for performing all activities was slower, but pacing gave a sense of control, and control was vital when making lifestyle changes. Changes in work patterns were also reported. Some participants no longer worked outside the home, however, for those who did, hours of work were reduced and the work environment was modified to meet their needs. For those who were unable to return to work, their lifestyle changes had a profound impact on self-esteem as well as the family income. Although pacing was viewed as a necessary strategy to manage FM, not all participants were happy with having to implement this strategy.

> I know I should pace myself but I hate that word, I can't stand the thought of having to pace myself. It just goes against my grain. I can't handle it, but I know I have to learn respect for that word.

Another related that she understood pacing was necessary but she found it frustrating when it took so long to accomplish specific tasks. She stated "I used to be able to do more on my lunch break than I can now do in two weeks."

By living within the boundaries most participants related strategies that were initiated to maintain a healthy lifestyle despite living with the chronic illness. These activities included taking naps, maintaining or increasing physical activities, avoiding alcohol and tobacco. They modified diets in response to an understanding of FM and included such changes as decreasing fats, monitoring salt and sugar intake. Other participants regularly visited massage therapists or a chiropractor. Some participants reported taking stress management courses. While some participants reported the use of prescribed medication, others reported the benefits received from alternate treatments of aqua pressure, multi vitamin preparations and visits to speciality clinics. Another participant disclosed that living within the boundaries motivated her to "exercise religiously, eat a high fibre diet and appreciate the good times more." As well, the value of personal exercise programs was vividly described in the following manner.

> Every exercise I can find I'll do. I'm really motivated to do my exercises. I really believe without the exercise I wouldn't be able to get out of bed. I start stretching before I get out of bed.

Each participant related how important it was to monitor health and to know what to expect with regards to a healthy life style in spite of FM. Several participants voiced fears that despite their personal health monitoring, whenever they experienced new symptoms, many physicians attributed these new symptoms to FM. These participants related that this attitude from their primary care physician placed them in a vulnerable position.

> You really worry that all those symptoms you are experiencing, are they related to FM? Or is there something else going on that might get overlooked . . . You find now that you get put off by the doctor.

> We all have to remember that there could be other things wrong with your body. Having FM puts you in a vulnerable position to have everything attributed to FM. I have to keep reminding my doctor of that. It's so easy to have FM the reason for everything. You could end up with something serious being overlooked.

Initially, participants knew little, if anything about FM, therefore another step in living within the boundaries was to become self-educated and thereby educate others including family, friends, physicians, employers and colleagues.

> I do believe now, though, that through reading about FM, I understand and know where things are coming from . . . . Like I've learned to change my attitude too, . . . now I know why some of these things are happening to me.

All participants believed that the key to dealing with FM was first to acknowledge its presence, by living within the boundaries. Living with FM was easier once you knew what you were dealing with. Most participants acknowledged that initially most of the fears associated with being diagnosed with FM was not knowing anything about the disease. Fear can paralyze. All the participants were seeking further support and information through the local FM self-help group and discovered that the group provided practical advice and moral support. The facilitators provided education and information. Psychological needs were met by the group members as the participants found others like themselves. The education program administered by the physiotherapy and occupational therapy department at a local city hospital initially provided information in a formal setting. Participants acknowledged that the self-help group and the education program were like "lifelines" for them.

> It was great knowing that someone else knows how you feel because they feel it too. Attending the group meetings help you find out that there are many others feeling just like you, they have feelings so similar to yours. You know now that you are not alone.

The awareness that resulted from learning about the condition and living within the boundaries helped them redirect precious energy into activities that enhanced their ability to cope with FM. Many contrasted their present feelings about the illness with these following the initial diagnosis. Receiving the diagnosis was compared to "stripping away the very fabric of their being." Many related that they felt their future was ominous, and still others wondered if in fact they would even have a future.

> My immediate reaction and concern were about what it [FM] would mean for me in years to come. What was it going to do to me, and what would I feel like as I got older.

Living within the boundaries was a result of being informed and knowledgeable, and was another means of control. Each participant revealed how knowing what to expect assisted them in making choices about how they lived with FM. Some of these choices may be viewed as simple by the casual observer, however for these participants, making an inappropriate choice had devastating effects on their well being. An example of such a simple choice for one participant was whether to wear high heeled or flat shoes, since high-heeled shoes precipitated extreme back and knee pain and caused problems with her sense of balance.

Living within the boundaries improved compliance to regimens, hence health and well being were improved. The participants reported that educating themselves and significant others about the condition played a vital role in how they accepted the condition and tried to live a productive life in spite of the limitations of the illness.

Acceptance in this sense, was not viewed by the participants as submitting to FM, or loosing control of the situation, but rather as a means of acknowledging what was occurring within themselves and understanding the limitations imposed by FM.

One participant recommended that others living with FM should focus on their strengths and not on the challenges they faced. She recognized that FM was a chronic lifelong illness and therefore while "living within the boundaries" she would not allow FM to be the central focus in her life. She stated:

> I have to be aware of what is going on in this area - but I can't let it consume me. I have to move on with my life as best I can

This participant, in sharing hope for the future for herself and others with FM, gave solid advice.

> You have to be strong, you have to take control of this and yourself, and do what you can for yourself because you are your own best friend . . . You are the only one who can make a difference for the good in this complex condition which you have to live with on a daily basis.

Other participants, as they lived within the boundaries, hoped that their experiences of managing to live productive lives with FM would be used to communicate advice to others who were struggling to live with the condition. The participants who believed they were coping well, felt they had worthwhile advice to share. As one participant stated: "sometimes I wish I could help other people develop a positive attitude about it [FM]." Without this strength of character and determination, as the participants lived within the boundaries, hope for a better tomorrow could only be a mirage, a dream.

Relationships Among Thematic Statements

Each theme previously discussed had a connection to the whole of these women's lived experience as they confronted FM daily. As such, the themes cannot be viewed as separate parts or segments but rather they must be seen as being intertwined with each other to form a total picture of the phenomenon, the experience of living with FM. Therefore, all of the themes formed an integral and interrelated picture of what it was like to live with the complex condition. All participants in assessing their experiences of living with FM related stories about the constant presence of pain. Pain, constant or intermittent, was always present, sometimes less severe than other times, nevertheless, always there. For all participants, learning to live with the pain was a major challenge. Measures which alleviated pain one day would not necessarily control their pain the next day or the next hour. One participant revealed that it was necessary to become friendly with the pain because it was always going to be around, to some degree.

Fatigue - the invisible foe was closely associated with the constant presence of pain. Fatigue was described as a total body feeling of exhaustion, and not merely a tired feeling. Like pain, fatigue was not predictable in its occurrence or severity, and like pain, pretending it did not exist, did not make it disappear. Like pain, fatigue was always there in some measure. So it was with these women's lives, the pain and the fatigue severely affected how they approached life.

Another prominent theme throughout the study was the participants' concern over the many sleepless nights. Unlike most persons, it was impossible for those women with FM to experience a good night's sleep. Sleeplessness for them was associated with many hours of being alone while other family members slept. Sleeplessness was as much a part of their life as pain and fatigue. Many referred to the sleeplessness as a factor which precipitated the pain and fatigue and viewed these factors as spokes in the pain/stress cycle.

As well, mental difficulties or "thinking in a fog" were viewed by many to be in direct proportion to the fatigue brought about by pain and sleeplessness. As some of the participants described their brains as "being wrapped in cotton wool" or "being in a fog," many wondered if having a good night's rest would decrease these undesirable feelings.

The unpredictability of a flare-up, or when some symptom was going to occur, was experienced by each participant. The certainty of the unpredictability of symptoms often caused anger and frustration. For most, they could not even entertain spontaneous actions, nor could they make long-term plans. This was a source of endless frustrations since under normal conditions most people participated in either or both of these actions. Therefore, being faced with this dilemma forced many to evaluate how successful they were in living a "normal life." Unpredictability of a flare-up was a normal pattern of life for them. The unpredictability of knowing when a flare-up would occur was also compromised by the uncertainty of mixed messages being sent by many health care providers.

Despite the pain, fatigue, sleeplessness and mental confusion, all participants expressed a desire for a return to normal life for themselves and their family. Measures to conceal the illness often resulted in expenditure of precious energy causing increased fatigue levels, which in turn, precipitated the pain to a greater degree of severity. After the condition had been named or a diagnosis given, the participants all realized that their symptoms were not imaginary. Participants then attempted to regain some measure of control over their lives. This control was facilitated by acknowledging the condition and by living within the boundaries imposed by FM.

Living within the boundaries assisted the participants to change lifestyle habits, to become educated concerning the condition, and to pace activities. This knowledge assisted participants to deal successfully with the limitations and challenges brought by FM. Being aware, allowed them to plan and to take measures which reduced pain, fatigue and sleeplessness. By living within the boundaries these women understood that the uncertain or unpredictable nature of the symptoms was a "normal" course of events for patients with FM. For all, the internalization of this information allowed them to exert some degree of control over their lives in their persistent struggle to confront and overcome the challenges presented on a daily, and for some, an hourly basis. A desire to help others similarly afflicted, and a hope for a satisfactory treatment, if not a cure, was the momentum that pressed these women forward.

The Essence

The essence or "what makes this experience what it is" was captured as "living with or continually confronting an invisible disability." The baffling and complex symptomatology of this condition was the foundation of what it was like to live with FM. These symptoms of pain, fatigue, sleeplessness, mental confusion, and other features of the condition such as unpredictability and uncertainty, and the need to live within boundaries, and longing for a normal life as they searched for a diagnosis were themes which succinctly captured living with FM's symptomatology and resultant invisible disability.

The developing awareness that something was wrong was subtle and gradual for some participants, whereas for others it was more pronounced. The multiplicity of some vague symptoms, while others were more intense, did little to assist the physician in making a diagnosis. How could one person have so many ill symptoms and yet visibly present a picture of health? One participant reported "I feel like a fraud." No one saw her pain, her mental confusion and the extreme fatigue that reduced the quality of her life.

Another participant experienced feelings of low self-esteem and saw herself as 'good for nothing'. Unsure of spousal support, she had assumed he also thought she was just being lazy. Her husband was very confused, since outwardly she looked so well and appeared disinterested in her home and their life together. After all, she was continually visiting the doctor and those visits did not result in a diagnosis. "Surely," he said, "if there was something physically wrong with her, all the tests and x-rays would have shown it by now." But how can anything invisible be seen?

Little did her husband, and others like him, realize that FM is a condition which is not readily or easily seen by the casual observer. Often this condition is elusive even to the primary care physician. FM provides no atypical appearance, no readily observable physical limitations and often cues are not visible by other individuals. Having FM has dual connotations. On one side, sufferers desperately try to conceal the condition, while on the other side, frustration is paramount because they sometimes perceive a lack of support or belief from others concerning the condition. However, all participants wondered how others who had no parameters to measure the illness could be expected to believe its seriousness. All participants experienced the misunderstanding of many friends, some family members, co-workers, employers and health care providers. Each participant mentioned that the reason for these misunderstandings lay in the incongruencies between how well they looked and how badly they felt. These participants believed "that if they had been disfigured, used crutches or needed a wheelchair the reaction and acceptance from others would be different." They firmly believed that the reaction would be more conciliatory and accepting. Their stories related these observations:

> If you have something wrong that people can see like a broken arm, surgery or something else that can be seen, then its okay, yes they can see the problem, but for others, if they can't see something, they need "blind faith" to believe that there is something wrong . . . . It's almost impossible for them to understand.

> Nobody really understands this condition. You do your best to look as good as you can, then somebody looks at you and says "what in the hell is wrong with you,

> there's nothing wrong with you." This makes me very angry, because no one understands how long it takes me to look decent.

All the participants related that the degree of discernable disability was dependent upon the amount of interaction with the individual. For many, while they concealed some of the symptoms from friends, it became more difficult as time went on to conceal the symptoms from family and work associates. Close acquaintances noticed the invisible disability when it became more visible as physical and cognitive disabilities became recognizable. In the meanwhile, these women, along with the other challenges, coped with a society which viewed them as "malingers" or "looking for attention" while they attempted to adjust and to acknowledge the limitations of FM with its outward invisible disability.

One participant revealed that because of FM she felt as if she did not "fit in" with her old acquaintances anymore. Prior to being diagnosed with FM she was labeled "the life of the party," now she felt useless, listless and tired all the time. She remembered the profound feelings of not fitting in, of not being asked to participate in a group. Even though her friends did not openly verbalize their confusion and disbelief at the severity of her symptoms, she felt a distinct distancing from her as they wondered why it was she could do volunteer work, yet could not return to her former job. Little did they realize that because of her invisible disability and the intense physical demands of her job, it was impossible for her to continue her career. However, she personally controlled the amount of time spent on volunteer activities.

Coming to terms with the invisible disability was particularly difficult for the single mother of two adolescent children. Most of the physical and emotional support expected from her spouse was now provided by her children. She regretted having to place so much responsibility on them for physical chores. She felt that casual observers, unaware of her condition and considering she looked so well, criticized her for having her children perform more than the usual amount of household chores. Often she chose to ignore her invisible disability and attempted to carry out tasks she knew only too well were detrimental to her condition. It was when a "flare-up" occurred she knew the strength of her invisible disability.

> On times I feel that I am not able to give my children what they deserve; what I'd like to give them and what I can give are two different things . . . but I do as much as I can. I have to make adjustments.

Because of the nature of FM, with its lack of physical signs being discernable, many friends, family and physicians expected the participants to "get on with it". Sometimes these acquaintances covertly expressed the view "she could do more if she wanted to" or "she looks perfectly healthy to me." Such remarks and attitudes often discouraged the individual with FM from seeking treatment or from adhering to the limitations of the condition.

Another participant reported that because most of her losses were discernable only to her, mourning those losses was not condoned by her family and friends. To mourn for a loss, people generally expected the loss to be visible like the loss of a spouse, the loss of a limb, the loss of a cherished object, or the loss of a job (Fitzgerald & Patterson, 1995).

The person with FM had losses which were less visible to the onlooker, subtle functional losses, subtle cognitive losses, social losses, loss of youth and a future, loss of friends, loss of the ability to be spontaneous, loss of a good night's sleep and the loss of the ability to "just enjoy life". Even when she allowed herself to mourn for her losses, one participant recalled how she felt.

> Some days I'd be so bad I wouldn't be able to get out of the chair and I'd say to myself "how dare you." " How dare you feel sorry for yourself, you're not going to be deformed or die. You can learn to live with it. Here is your friend who has cancer . . . and she is determined to beat this." So how can I turn around and complain about FM.

Others felt guilty mourning the losses brought about by the invisible disability as they realized that there were other conditions with more serious effects. One participant related "I know multiple sclerosis is so much more catastrophic than FM."

The invisible disabilities encountered as one lived with FM, made FM different from other conditions. The person with FM needed to be aware that there was a danger in personally ignoring invisible disabilities. Allowing perceptions of roles and expectations of others to influence personal knowledge of the condition often pushed them beyond their normal capacity, and subsequently hindered acceptance of the condition and its limitations. These reactions had far reaching effects on the FM sufferer and her family, since acknowledgment of FM allowed one to exert commitment and courage to meet the challenges of living with FM.

CHAPTER 5: DISCUSSION

The aims of this phenomenological study were to describe and understand how women live with FM. The understanding or interpretive sense was made by examining each theme in relation to current literature. For all the participants, the knowledge that "something was wrong," caused them to be discouraged and created misunderstandings about the nature of the illness. For many, the search for a diagnosis necessitated many frequent and unnecessary tests and examinations. Subsequently, when they could not find or provide a physical explanation for the symptoms, many practitioners suggested psychotherapy and stress management. Similar negative tests and examination results were also described in the study by Schaefer (1995).

For those who received a diagnosis, knowing the condition did not exist only "in their head" was a relief. However, for many, after being given a diagnosis, they still needed to find a cause or meaning for what had happened. These findings were consistent with previous studies which examined women's perspectives on chronic illnesses (Anderson, Blue, & Lav, 1991; Fife, 1994). Fitzgerald and Patterson (1995), Skevington (1986), and Telles and Pollack (1981) also reported that persons with chronic pain will go to considerable lengths to seek legitimization of their illness from family, friends and physicians and the fear that others perceive them as malingers was always present. So it was with women in this study. The participants reported that they were not taken seriously either by health care providers, family, or friends, and they felt that no one believed the severity of symptoms because they looked so well.

The findings from this study show that FM with its chronic, relentless, generalized muscular pain caused profound negative changes in all the participants' lives. For those who performed physical tasks and who worked outside the home, extra time and effort were required, often at a cost of increased pain severity. Similar findings were discussed by Yunus et al. (1981). In terms of pain and global debility, FM was experienced as more severe than any other chronic pain syndrome (Boissevain & McCain, 1991). In this current study, pain was outlined as one of the main sources of considerable distress for each of the participants.

In a study by Hagglund et al. (1994), patients with chronic pain frequently reported that weather condition negatively affected their pain. In a similar study by Shutty, Cundiff and DeGood (1992), cold and damp variables were cited to be the most problematic. In this study, however, most of the participants believed that their pain was influenced by actual changes in atmospheric pressure rather than by the cold, damp, warm or dry conditions.

Stuifbergen (1987) indicated that the stress of chronic illness could dissolve a family unit. Henriksson (1995) reported that fear of physical contact by the FM sufferer strained martial relationships. In this study, many participants recounted stories of strained family relationships. In one incident, a marriage dissolved and the participant attributed this in part to the stress of the chronic illness, and the pain she continuously experienced along with the fear of being touched. As well, many of the participants avoided areas such as shopping malls and elevators because of the possibility of being accidentally bumped or touched.

Watson (1992) suggested that the family's ability to cope and adapt to a chronic illness was probably influenced by its developmental stage. For parents of young children there were more physical tasks related to their care. If one parent was chronically ill, extra demands were placed on the other parent. The findings of this study are consistent with the literature since women who had young children believed that they had more demands placed on them. Such demands were often left unfulfilled unless the other parent assumed that obligation.

Loss of the ability to function physically and mentally necessitated many role changes within the family structure. It was harder for some than others to accept help for specific tasks, and more difficult for other family members to adapt to changing roles. Inability to relinquish former roles and to take on new ones was a source of frustration and anger for some of the participants in this study. These observations were consistent with other findings on chronic illness and role adaptions (Brown & Williams, 1995; LeGallez, 1993; Revenson & Majerovitz, 1991).

Fatigue, sleeplessness, and mental confusion were also identified as core themes in the analysis. One study which examined the fatigue experienced by persons diagnosed with MS described fatigue as a feeling of total bodily exhaustion (Hubsky & Sears, 1992). These findings related to fatigue for patients with MS were consistent with the views expressed by participants in this study. Interestingly, several of the participants in this study were screened for MS in earlier stages of the diagnostic process. Hubsky and Sears also indicated that sleeplessness and mental confusion were interrelated and negatively influenced subjects diagnosed with MS. These findings related to MS were also consistent with the findings in this study.

Dealing with the unpredictability of the symptoms associated with FM caused much anxiety and frustration for the participants in this study. The unpredictability of accelerated symptoms made life unbearable for some. However, others slowly learned to accept this characteristic of the illness as something they had to deal with on a daily basis. Others found the unpredictability of their symptoms caused conflict in the enactment of their roles, relationship to family and friends, and in their ability to hold a job. Lambert and Lambert (1987) and Stuifbergen (1990) presented similar findings.

The uncertainty of not knowing what was happening, or why it was happening, was a theme which was threaded throughout the interviews. Uncertainty was seen as a major source of stress for persons with chronic illnesses. The concept of uncertainty was described by Hilton (1988). In her study, women with breast cancer found that a major source of uncertainty was not being able to rely or count on someone. Women in this study reported similar feelings of uncertainty. For the most part, the uncertainty of not knowing what was happening was experienced because many believed that their primary health care providers did not understand their condition. Statements such as "how can my doctor help me help myself if he doesn't understand the condition" and "one doctor will say do this or do that while another will condemn that treatment" were evident throughout the interviews. This type of uncertainty was consistent with the findings by Mishel (1988) since the uncertainty in this study also stemmed from ambiguous symptoms, inadequate information, and delay in receiving a diagnosis.

How well persons with a chronic illness adapted to limitations imposed by the illness was influenced by the interpersonal relationship of social support. Social support promoted well-being and helped persons cope with challenges during stressful life circumstances. Results from this study indicated that persons with FM appeared to adjust better if there was support from significant others. This support was not immediate as an understanding of the condition was needed by the supporter. This information is consistent with research by Bloom (1990), Fitzpatrick et al. (1989), Lanza and Revenson (1993), and Primomo, Yates, and Fugate-Woods (1990). Participants in this study also described the benefits of knowing that they were not alone with this condition, and how they looked forward to group meetings and educational sessions. These encounters provided them with a conducive forum for relating to others with similar experiences. These findings are consistent with Marr (1995).

In addition to the positive influence of social support on the health and well-being of persons with a chronic illness, the importance of the concept of self-efficacy was evident to some degree in this study. This was suggested as participants related that they believed they could control FM and not let FM control them. For others the strength of their convictions to be efficacious was illustrated as they expressed a desire to move on and to be a helpful influence to others newly diagnosed with FM. Literature disclosed self-efficacy's importance in relation to coping with chronic pain (Gonzalez, Goeppinger, & Lorig, 1990; Jensen, Turner, Romano, & Karoly, 1991; Kores, Murphy, Rosenthal, Ellias, & North, 1990).

Living within the boundaries was another coping procedure used by the participants to exert control over FM. Having a name applied to the symptoms allowed them to make adjustments in plans and to move on. Others living with chronic illnesses made the same kind of concession described by Howell (1994) and Schaefer (1995). Attempts to have a normal family life, and to be seen as having that kind of life, were evident throughout all accounts by the participants. To accomplish this task, women in this study applied tactics such as concealing or covering up, doing normal things at a substantial cost, making trade-offs, pacing, and eliciting assistance. These measures were explored in the literature pertaining to living with other chronic illnesses (Knafe & Deatrick, 1986; Marr, 1992; Robinson, 1993; Wiener, 1975). Likewise the women in this study sometimes made important problems seem insignificant to their health care providers, and as a result, on occasions, the necessary support was withdrawn.

The stress of dealing with an invisible disability added to the frustration and anxiety for each of the participants. The dilemma of how well they looked in relation to how unwell they felt was a cause of conflict not only for themselves but also other family members, friends, physicians, and employers. Most participants reported that negative statements and unfriendly looks were often given when they talked about their inability to meet expectations and act as they previously did. After all, they looked the same. The results of these interactions negatively influenced persons with FM as they tired of explaining their behavior. These reactions resulted in lower self-esteem and social isolation as the numbers of close friends and social contact diminished. Falvo, Allen and Maki (1982), and Fitzgerald and Patterson (1995) discussed similar findings as they reviewed diabetes, epilepsy and other medical conditions which did not provide an atypical appearance or readily observable functional limitations.

As well, many participants felt that being diagnosed with FM was an impediment to satisfactory health care regarding other health and personal issues. This feeling of mistrust toward the medical profession had the potential of having devastating effects because other serious illnesses often went undetected as all symptoms were perceived to be related to FM. Some participants believed this attitude was due in part to the fact that most patients with FM are females in a mostly male medical society. This feeling of mistrust is supported by Brown and Williams (1995)

Summary

The findings of my research study are similar to those found in other research studies which investigated FM and other chronic illnesses. Having a label or name attached to the symptoms is very important since validation of the symptoms legitimatizes the illness. In terms of pain and fatigue, research consistently identified FM to be more debilitating than other chronic illnesses. These symptoms were intensified by fluctuations in weather conditions and other stressful life situations such as dealing with the unpredictability of symptoms, the uncertainty of knowing what to expect, and losses associated with the condition. This study reveals that the stresses associated with FM have negative outcomes for the family. Younger families seem to more negatively affected.

The value of social support and self efficacy on health and well being for persons with FM is evident throughout the study. These concepts assist persons with FM to have control over the illness. As well, living within the boundaries and acknowledging the condition allow participants in this study to exert control over the condition. While the participants felt that they were moving on by becoming knowledgeable about FM, many believed that dealing with an invisible disability had many negative connotations.

CHAPTER 6: LIMITATIONS, IMPLICATIONS FOR FUTURE NURSING EDUCATION, PRACTICE AND RESEARCH, AND CONCLUSION

Facing a life with the chronic illness of FM is a significant crisis for participants in this study because of the major challenges presented by this condition. Therefore, the findings of this study, despite its limitations, have implications for future nursing practice, education and research.

Limitations

In this study, data were collected by means of unstructured interviews whereby participants were invited to give an account of their experiences. These participants were selected to be in the study, based on their knowledge of, and ability to articulate, the experience of living with FM. While most participants were able to articulate distinctly the meaning of this experience for them, others required prompts. This prompting may have forced some participants to say what they thought I wanted to hear rather than provide reflective descriptions of the experience.

There was a wide range in the age of the participants, as well as a variation in the number of years each had lived with the condition. The age range placed them at different developmental stages in their lives, and hence may have influenced how they perceived their experiences. As well, having experienced the condition for a longer period of time may have influenced coping interventions used to manage the condition.

The study comprised of women who had very young, adolescent, and teenaged children at home, and adult children living at or away from home. These differing ages in children may have been factors that influenced the perception of the severity of the condition for some participants more than others. Certainly younger children place more physical demands on parents than most older children.

Additionally, this study was conducted with a group of women who resided in an urban area. The results may have been different if the study had taken place in rural Newfoundland. The perceptions of support systems and access to information may be different between the two areas.

Finally, the results of this study cannot be generalized to the total population living with FM, nor can it be used to provide a definite model for future care. However, its message regarding support systems, the value of having some control, and the impact of a mother's chronic illness on the family cannot go unheeded as primary care nurses provide holistic, individualized care to women with FM and their families.

Implications

Nursing practice and education

Professional nursing practice implies that caring is the essence of nursing and the unique and unifying focus of the profession (Leininger, 1985). Nurses can be pivotal in bringing about interventions through their caring, and they can limit the powerful impact that chronic illness has on individuals and their families. Literature indicated that dealing with a chronic illness not only affected the person with the illness but also the whole family