

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

# **Patients' Perspectives on Fibromyalgia Syndrome (FMS)**

*A thesis presented in partial  
fulfilment of the requirements for the degree  
of Master of Arts in psychology  
at Massey University*

**Maggie Cheng**

**1999**

# Abstract

Fibromyalgia Syndrome (FMS) is a chronic musculoskeletal pain syndrome of unknown origin and uncertain prognosis. In this study, patients' perspectives of their experiences of fibromyalgia syndrome (FMS) were explored using grounded theory methodology. Of particular interest were their perspectives on aetiology, symptoms, intervening conditions, coping strategies, and consequences of FMS. Eight FMS sufferers participated in one-to-one in-depth semi-structured interviews. Interview transcriptions were analysed using Strauss & Corbin's (1990) paradigm model of grounded theory. Findings indicate a degree of conceptual overlap with previous literature in terms of the known aetiology. However, new evidence appeared in the form of a combined reactive, idiopathic onset, with more support for a multifactorial FMS aetiology. Further, familial and heredity factors emerged as more significant aetiologies than was previously suspected for FMS sufferers'. Symptoms for the present sample parallel to those of the literature. Specifically, both chronic pain and fatigue emerged as the most salient and disturbing symptom of the FMS experience. Pain assumed the role of the basic social process (BSP) in the core category that summed up the FMS experience. One new crucial finding was the degree of cyclic association between pain, fatigue, and sleep disturbance, which interacted to create and maintain other FMS symptoms. Public and professional misperceptions, medical assistance, and knowledge of the condition emerged as important intervening conditions in the present population. Positive deferral emerged from the data as a new cognitive coping strategy. Moreover, a link was supported between cognitive coping strategies and self-efficacy. A new emergent pattern for FMS sufferers revealed an evolution in the type and application of coping strategies. Consequences of FMS condition fluctuated and varied among patients according to various intervening conditions. The report discusses implications for patients, health professional and researchers. In general, the patients' perspective and dialogue on their own condition should be given greater weight in the diagnosis and treatment of FMS.

## **Dedication**

I would like to dedicate this thesis to my late grandfather, Chao-Chieh Chuang, whose memory lives on in my heart. Your value of higher education instilled in me a desire to achieve.

I dedicate this thesis to my family, particularly my father and mother, Nien-Tsu and Yueh-Ling Cheng. Your love and unwavering support guided me to where I now stand.

## **Acknowledgements**

The long and arduous road that represents the construction of this research project pale in comparison to the pain continually endured by those afflicted with Fibromyalgia.

In researching and writing this report, I looked for the guidance and support of many talented individuals. Firstly, I would like to express my gratitude to my supervisor, Malcolm Johnson, for providing me with a rewarding topic and a depth of insight into issues of chronic pain and health psychology.

I furnish an equal level of gratitude to my secondary supervisor, Dr. Mandy Morgan, for her vital guidance and expertise in all matters of grounded theory research.

I am indebted to my close friend and colleague, Warren Saunders, for his support as a friend and for his technical assistance with editing and fine tuning of the analysis and written research report.

A special thanks to Michelle Strand for her editorial expertise.

No research, no matter how elaborate in design and planning is realised without the time and patients of the research participants. This is particularly the case with the present research where participants shared their experiences in prolonged in-depth interviews under conditions that may have aggravated their condition. I would like to express my deepest appreciation to all those Fibromyalgia patients for their willingness to discuss their condition. Through your time, I hope that this research may go some way towards alleviating you of your pain.

# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	I
ABSTRACT .....	II
CHAPTER 1 CHRONIC PAIN PATIENTS' EXPERIENCE OF PAIN: DETERMINANTS & OUTCOMES OF CHRONIC PAIN .....	1
Personality Variables .....	3
Physical Variables .....	4
Psychological & Emotional Variables .....	5
Cognitive Variables .....	7
Medical-care Variables .....	9
The Link between Chronic Pain & Fibromyalgia Syndrome (FMS) .....	10
Conclusion .....	11
CHAPTER 2 FIBROMYALGIA SYNDROME (FMS): CLASSIFICATION, DIAGNOSIS, PROGNOSIS, & SYMPTOMS .....	12
The Definition .....	12
The Diagnosis .....	14
FMS Symptoms .....	14
The Prognosis .....	15
Chapter Summary .....	16
CHAPTER 3 THE METHODOLOGY .....	17
Grounded Theory .....	17
The Present Study .....	22
Methodology for Data Collection .....	24
Methodology for Data Analysis .....	30
An Explanation for the Thesis Structure .....	36
Chapter Summary .....	37
CHAPTER 4 THE CORE CATEGIRY: LIVING WITH CHRONIC PAIN .....	38

<b>CHAPTER 5 THE CAUSAL CONDITIONS OF FMS .....</b>	<b>46</b>
Specific Onset .....	46
Specific & Non-specific Onset .....	47
Comparative Effects of Reactive & Idiopathic Onsets .....	51
Theories of Hereditary Causality .....	52
Chapter Discussion .....	53
 <b>CHAPTER 6 THE PHENOMENON .....</b>	 <b>56</b>
Pain .....	56
Energy Reserve .....	62
Central & Peripheral Nerve System .....	64
Visceral System .....	65
Musculoskeletal System .....	65
Psychological Symptoms .....	66
External Influences .....	70
Chapter Discussion .....	70
 <b>CHAPTER 7 THE INTERVENING CONDITIONS .....</b>	 <b>72</b>
Financial Intervening Conditions .....	73
Person-oriented Intervening Conditions .....	75
Medical Intervening Conditions .....	78
Information & Awareness Intervening Conditions .....	83
Social Support Intervening Conditions .....	85
Discussion .....	89
 <b>CHAPTER 8 THE COPING STRATEGIES .....</b>	 <b>91</b>
Cognitive Coping Strategies .....	92
<i>Discussion</i> .....	97
Behavioural Coping Strategies .....	99
<i>Discussion</i> .....	107
Cognitive-Behavioural Coping Strategies .....	108
<i>Discussion</i> .....	113
Family & Social Support .....	114
<i>Discussion</i> .....	119

Perceptions of Emotional State .....	120
Chapter Discussion .....	126
<b>CHAPTER 9 THE CONSEQUENCES .....</b>	<b>129</b>
Illness Impact on Health & Related Matters .....	130
Illness Impact on Emotions .....	138
Illness Impact on Social Relations .....	143
Illness Impact on Employment .....	147
Illness Impact on Relations with Health-care Services .....	153
General Impact on Living with Chronic Pain .....	161
Chapter Summary .....	165
<b>CHAPTER DISCUSSION .....</b>	<b>166</b>
Discussion of the Present Findings .....	167
Limitations of the Study .....	178
Implications for Future Research .....	179
Implications for Medical Practitioners & Significant Others .....	182
<b>REFERENCES .....</b>	<b>184</b>
<b>APPENDIX I CRITERIA FOR JUDGING QUALITATIVE RESEARCH .....</b>	<b>197</b>
<b>APPENDIX II INTERVIEW QUESTIONS .....</b>	<b>200</b>
<b>APPENDIX III FACE SHEET .....</b>	<b>204</b>
<b>APPENDIX IV NEWSPAPER ADVERTISEMENT .....</b>	<b>205</b>
<b>APPENDIX V INFORMATION SHEET .....</b>	<b>206</b>
<b>APPENDIX VI CONSENT FORM .....</b>	<b>208</b>
<b>APPENDIX VII SUMMARY OF FINDINGS LETTER .....</b>	<b>210</b>

# LIST OF FIGURES

Figure 1: The association between stress, illness, and a third variable .....	6
Figure 2: Cognitive-behavioural model of fear of movement/(re)injury .....	8
Figure 3: The paradigm model .....	32
Figure 4: The association between person-oriented intervening condition, medical intervening condition, and financial intervening condition .....	74

## **LIST OF TABLES**

Table 1: The intervening conditions of FMS sufferers' experience .....	72
Table 2: The four categories of FMS sufferers' coping strategies .....	91
Table 3. A classification of the overall impact of FMS on sufferers .....	129

## CHAPTER ONE

# **Chronic Pain Patients' Experience of Pain: DETERMINANTS & OUTCOMES OF CHRONIC PAIN**

Pain is a personal experience that is usually a symptom of disease or injury (Bond, 1987). Irrespective of its cause or severity, experience of pain involves changes in both emotion and behaviour. The International Association for the Study of Pain (IASP) defines pain as *"an unpleasant sensory and emotional experience associated with actually or potential tissue damage, or described in terms of such damage"* (Merskey & Bogduk, 1994, p. 210). Pain responses modify according to a pattern of characteristic interactions of physiological mechanisms with behavioural, emotional, cognitive, and social variables (Horn & Munafo, 1997).

Within the broad definition of pain, specific types and categories of pain can be identified according to their individual aetiology, symptoms, regions, temporal characteristics, and duration. The present investigation is primarily concerned with chronic pain, which broadly refers to pain of at least several months' duration (Sternbach, 1982). More precisely, chronic pain refers to a category of pain whose longitivity persists beyond the expected time for recovery and whose stimulus is not well defined (McGrath, 1993). Further, chronic pain has been defined as a persistent stressor that frequently contributes to disability and produces numerous coexisting problems (Jamisons & Virts, 1990). These definitions exhibit a conceptual overlap in the duration ascribed to chronic pain, yet differ in that McGrath's definition focuses on the source, while Jamison & Virts' focuses on the generic outcomes of chronic pain. In any case, all definitions provide valuable insights into chronic pain condition.

Individual responses to chronic pain range from minor disruption to daily life to total impairment (Haythornthwaite, Menefee, Heinberg, & Clark, 1998). The effects of chronic pain many include sleep disturbance, appetite change, irritability, decreased libido, withdrawal from social interaction, and increased somatic preoccupation (Sternbach, 1982). Chronic pain can also contribute to medication dependence and physical inactivity (Vendrig & Lousberg, 1997). There are also possible emotional

consequences, such as a sense of helplessness and alienation, low self-esteem, depression, anxiety, fear, and demoralization (Rudy, Kerns, & Turk, 1988; Vendrig & Lousberg, 1997). Chronic pain also produces a ripple effect, impacting on non-sufferers through interference with interpersonal relationships between sufferers and significant others (Roy, 1989). Thus, as a condition, co-condition, or symptom, chronic pain severely impairs the physical functioning, mobility, independence, and quality of life of millions of people (Becker, Thomsen, Olsen, Sjogren, Bech, & Eriksen, 1997). Many of these pain sufferers are either partially or totally disabled for periods of days, weeks, months, or permanently.

Because of the enormous economic, social, and personal costs of chronic pain, many research efforts have focused attention on identifying variables that predict the onset of chronic pain. Consequently, many variables have been shown to relate to pain chronicity, although the nature of the causal relationship is not known given that most studies are cross-sectional. However, prior research suggests that the development of chronic pain appear to relate to an interaction of several variables. For instance, age, gender, ethnic group, marital status, educational qualification, occupation, and employment status, medical, physical, psychological, cognitive, and pain variables (White, LeFort, Amsel, & Jeans, 1997).

Of the more credible predictors, pain intensity assessed prior to the development of chronic pain, is considered one of the most consistent predisposing factors in the progression of chronic pain (White et al., 1997). Some studies have found age and educational level predictive of chronic pain progression. For instance, Baumstark, Buckelew, Sher, Beck, Buescher, Hewett, & Crews' (1993) study identified two significant predictors of pain behaviour: age and physical disability. That is, the older the sufferer, the more evidence of pain behaviours. Additionally, most sufferers who showed greater pain behaviour were overweight in term of their body mass index. In terms of susceptibility, chronic pain is reported to be more common among women (Crook, Rideout, & Browne, 1984). However, follow-up studies have failed to find these relationships, including Peters & Schmidt (1991).

In patients whose pain follows illness or injury, two dimensions of morbidity – activity level and diagnosis – have been found to predict the development of chronic pain. Chronically ill patients who are bedridden or have low activity levels tend to develop chronic pain. White et al. (1997) found fractures and trauma were predictive of a

progression of chronic pain. Ty, Melzack, & Wall (1984) also found accident victims with more severe injuries were more likely to develop chronic pain.

More recently, White et al. (1997) identified a set of variables that predicted the development of chronic pain better than any single variable. Their multivariate analyses confirmed that chronic pain is a complex phenomenon that develops from, and is augmented by personality, psychological and emotional states (i.e., stress and depression), physical condition (i.e., musculoskeletal disorder), cognition, and medical variables. The following sections will examine in more detail the significance of these predictors to the development of chronic pain. However, as many of the studies that examined these relationships are cross-sectional and correlational with the direction of causality been unclear. Furthermore, the method of reciprocal or cyclical causal relationship makes the discussion of causality difficult and therefore the following sections will discuss the predictors and consequences of chronic pain jointly. The following discussion presents an overview of an enormous body of literature. It attempts to provide a background of chronic pain in the context of Fibromyalgia Syndrome (FMS).

### **Personality Variables**

Various personality variables appear crucial for determining the extent, nature, and severity of the psychological symptoms of chronic pain (Bond, 1979, cited in BenDebba, Torgerson, & Long, 1997). Several researchers have investigated the associations between neuroticism and extraversion and chronic pain severity with psychological distress under both experimental and clinical conditions (Harkins, Price, Braith, 1989; Wade, Dougherty, Hart, Rafii, & Price, 1992). Among the more relevant findings, extraverts were found to tolerate pain better in experimental conditions, but exaggerate pain in a clinical situation compared to introverts (Horn & Munafo, 1997). Moreover, moderate positive correlations have been demonstrated between psychological distress and neuroticism, and between psychological distress and extraversion in chronic pain patients. BenDebba et al (1997) concluded that there is a distinct positive relationship between psychological distress and neuroticism. They showed that degrees of psychological distress were associated with personality attributes and illness features, regardless of the patients' history of complaint of pain severity and functional impairment.

Recent studies have found a positive correlation between personality Type A behaviour and the incidence of various minor illnesses (Suls & Marco, 1990, cited in Weiten, 1992). It has been speculated that Type A personality is part of a *generic* disease-prone personality that predisposes people to a diverse array of health problems (Friedman & Booth-Kewley, 1987, cited in Weiten, 1992). However, the association between Type A personality variables and chronic pain remains unsubstantiated.

Another personality type referred to as *premorbid personality*, has been linked to chronic pain. For instance, both recent-onset and chronic subjects who were more socially active tended to manage their pain more successfully compared to *premorbid personality* individuals who were more socially inhibited (Holmes & Stevenson, 1990). Jamison & Virts (1990) observed that *premorbid personality* (such as introversion) might affect adaptation to the pain. They noted that *premorbid personality* variables 'impaired' chronic pain patients' interpersonal skills that underline the development and maintaining a social network important for social support.

### **Physical Variables**

A relationship has emerged through the literature demonstrating that pain leads to disability, which restricts physical activity. For instance, evidence from a Swedish investigation considering inactivity and disability resulting from pain, demonstrated that most pain participants exhibited associated complications and limitations in daily activities, including walking, climbing, and socialising (Brattberg, Thorslund, & Wikman, 1989). In another study, more than 50% of British pain sufferers interviewed reported an inability to work and lead a normal life (Bowsher, Rigge, & Sopp, 1991; cited in Astin, Lawton, & Hirst, 1996). Similarly, Astin et al. (1996) established a significant link between musculoskeletal disorders – the primary onsets of disability – and severely limiting pain. For instance, patients with severe disorders like arthritis, rheumatism, and other musculoskeletal disorders often suffered from weakened mobility and reduced joint functioning. Furthermore, an association was found between musculoskeletal disorders and complaints of severe respiratory, digestive, and genito-urinary system pain in a minority of disabled adults. Finally, severely limiting pain related to the presence and severity of disabilities in terms of sharing the same physical origin and impacts on physical mobility. Typically, these impacts include impaired locomotion, dexterity, precision grip, and reaching and stretching movements, which

affected independently or collectively the majority of chronic pain sufferers. Astin et al. (1996) concluded that the chronic pain experiences can profoundly disturb individuals' physical functioning, mobility, and independence on a daily basis by prohibiting them from living a normal life.

## **Psychological & Emotional Variables**

### **Depression**

Poorly managed chronic pain generate feelings of deep distress, hopelessness, and despair, which frequently leads to disruption of individual and family functioning (Craig, 1994; Rowat et al., 1994; both cited in LeFort et al., 1998). Magni, Moreschi, Rigatti-Luchini, & Merskey (1994) established a link between chronic pain and depression, although they were uncertain about the nature and direction of this relationship. Although the causal connection has not being established between the predictive and outcome variables, Magni et al.'s (1994) study appears to suggest that depression promote chronic musculoskeletal pain, with chronic musculoskeletal pain promotes depression. Research has demonstrated that individuals who exhibit depressive symptoms and reactions commonly suffer from chronic pain and, conversely, patients with chronic, non-malignant pain reportedly suffered higher frequency of depression (Romano & Turner, 1985) Krishman, France, Pelton, McCann, Davidson, & Urban, 1985; Magni et al., 1994). Even when depression is not reported, psychological assessments indicate that chronic pain sufferers are often depressed, though some may be unaware of their depressed mood due to their preoccupation with somatic symptoms which act to disguise their depression (Sternbach, 1982).

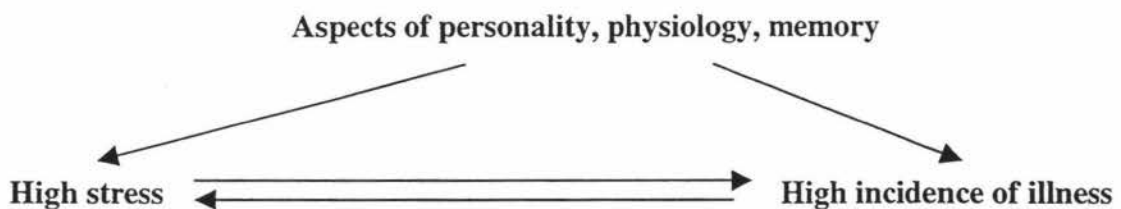
Several investigations have found that depressed chronic pain patients report higher levels of pain intensity (Haythornthwaite, Hegel, & Kerns, 1991). In an attempt to differentiate the effects of illness and pain on mood, Sist, Gerard, Marguerite, Miner, Lema, & Zevon (1998) compared chronic non-cancer pain patients with cancerous chronic pain patients. They found that the chronic non-cancer pain patients demonstrated a significant correlation between high levels of pain and severe depression, compared to cancerous chronic pain patients. They concluded that depression is related to both escalated affective pain intensity and the diffusion of affective pain language with the affective dimension of tension, fear, and autonomic properties which accompany nociception. Instead of the characteristics of the fundamental medical condition, it

appears that the presence of pain is the most relevant factor linked to the intensity of depressive symptoms.

Chronic pain patients whose activity levels are reduced are particularly predisposed to developing depressive mood (Rudy et al., 1988). Treatment of depression often significantly reduces chronic pain.

## Stress

A wealth of evidence shows that stress is related to physical health, and converging lines of evidence suggest that stress contributes to the *causation* of illness. However, most of the relevant research is correlational, which precludes the demonstration that stress causes illness. In many cases, subjects elevated levels of stress and illness could be both due to a third variable, perhaps an aspect of personality (Watson & Pennebaker, 1989, cited in Weiten, 1992). Much of the research has methodological limitations including correlational designs and retrospective identification of stressful events. Critics of these research designs have pointed out that many of the studies used methods that might have inflate the links between stress and illness (Schroeder & Costa, 1984, cited in Weiten, 1992).



**Fig. 1. The association between stress, illness, and a third variable**

In spite of methodological problems favouring inflated correlations, the research in this area consistently indicated that the *strength* of the relationship between stress and health is modest. The correlations typically fall in the .20 and .30 range. Clearly, stress is not an irresistible force that produces inevitable effects on health. This is not surprising, as stress is only one factor operating in a complex network of biopsychosocial determinants of health. Other key factors include one's genetic endowment, exposure to infectious agents and environmental toxins, nutrition, exercise, alcohol and drug use, smoking, use of medical care, and co-operation with medical advice. Furthermore, some people handle stress better than others. Even with such a modest correlation it is obvious that stress is among the more important moderating factors and, therefore, worthy of

further investigation. More persuasive evidence comes from work by Flor & Birbaumer (1985), who concluded that only personally relevant stress and pain conditions elicit marked increases in muscle tension at the site of pain.

In summary, it has been demonstrated in both clinical research and in anecdotal reports that chronic pain sufferers experience a wide range of emotional disturbances (Almay, 1987). Nevertheless, there is no confirmation for categorising psychological variables as predictors of chronic pain development, or as consequences of the experience of chronic pain (White et al., 1997).

### **Cognitive Variables**

Cognitive operations, consisting of attention, beliefs, and learning process, can modify both one's perception of and response to pain (White et al., 1997). The direction of causality between pain and cognitive variables remains ambiguous, although it is believed to be interactive (Horn & Mufano, 1997).

Waddell, Pilowsky, & Bond (1989) established a link between illness behaviour and psychological distress by suggesting that patient belief of illness untreatability is positively related to high increasing levels of distress. White et al. (1997) and Dworkin, Hartstein, Rosner, Walther, Sweeney, & Brand (1992) concluded that personal beliefs about the cause of pain are predictive of the tendency to develop chronic pain. Strong, Ashton, & Chant (1992) assessed pain in relation to patients' attitudes, beliefs, expectations, and its consequential treatment. They found that these variables can potentially influence patients' preference in treatment programmes since their pain-coping competence, consent to treatment, and subsequent treatment may be influenced by their attitudes and beliefs about their own pain experience. Therefore, one of the most consistent findings is that catastrophic thinking about pain is associated with higher pain and poorer performance in treatment.

Feelings of helplessness or catastrophic thoughts like "such agony is constant" are usually the result of, or reinforced by, somatic pain. Depression, with symptoms like helplessness and catastrophic thoughts, is typically experienced concurrently to chronic pain, with reciprocal causality. Main & Waddell (1991) reported that frequent catastrophic thoughts were associated with depressive symptoms, disability, and a loss of employment despite the manipulation of pain severity.

Research into pain-related beliefs shows that patients' beliefs that pain impairs function are predictive of range of motion, complaints of movement limitations, and reports of disability (Riley et al., 1988, cited in McCracken, 1998). That is, as patients increasingly believe that pain impairs functionality, functionality actually becomes more impaired. Moreover, believing that pain is disabling predicts both physical and psychosocial disability (Jensen, Turner, Romano, & Lawler, 1994), which influences individuals' coping success with chronic pain. Two associated interrelated factors proposed to sustain disability from chronic pain are fear and avoidance behaviour (Vlaeyen, Kole-Snijders, Boeren, & van Eek, 1995). Specifically, chronic pain patients' fear of pain and avoidance response has been shown to lead to disability because of physical disuse. For instance, Crombez, Vervaeke, Baeyens, Lysens, & Eelen (1996) and Waddell, Newton, Henderson, Somerville, & Main (1993) found that patient beliefs and expectations that movement (i.e. work) resulted in physical damage and increased pain was predictive of fear. Referring to this phenomenon as 'fear-avoidance beliefs', they found that patients fear of pain initiated a type of avoidance behaviour to physical activities that might induce pain. Around the same time, Vlaeyen et al. (1995) conducted a two-part study on fear of movement on patients with chronic musculoskeletal pain. Results from their research indicate that patients reporting a high degree of fear of movement and injury from movement reported greater catastrophising and depression, and less pain coping behaviour than those lower in fear of movement/(re)injury.



**Fig. 2. Cognitive-behavioural model of fear of movement/(re)injury**

(Vlaeyen et al., 1995, p. 368)

Interference with mental processes and subsequent interruption of current activities has been identified among the more disabling features of chronic pain (Eccleston, Crombez, Aldrich, & Stannard, 1997). Little research has been done on the significance of poor concentration, although it is a typical clinical complaint. Wall (1989) theorised that the attention mechanism, which serves to manipulate selective information into recognition, is relevant to the onset and continuation of chronic pain. Sufferers of chronic pain that demonstrated a heightened attentional focus on their physical state typically expressed more frequent physical problems. Consistent with Wall's theory, chronic pain patients who participated in Eccleston et al.'s (1997) study reported persistent and recurrent disruptions to concentration and short-term memory. Further, chronic pain patients show memory biases as illustrated by a fixation on pain-related words (Edwards, Pearce, & Beard, 1995).

### **Medical-Care Variables**

Preliminary epidemiological studies have shown that chronic pain represents a public health problem (Brattberg et al., 1989; James, Large, Bushnell, & Wells, 1991). Chronic pain complaints, particularly of musculoskeletal origin, are among the most frequent reasons for visits to the medical professional, and, on average, require more time per visit than any other type of health problem (LeFort et al., 1998). The need for the public health sector to improve health and social care benefits to chronic pain patients is crucial. This situation is largely the result of insufficient knowledge of the epidemiology of pain, which has inhibited relevant health care appraisal of national expenditure, evaluation of treatment efficacy, and service planning (Brook, 1994). Chronic pain leads to socio-economic problem for sufferers (White et al., 1997). Socio-economic issues impact on society in terms of consequences to sufferers that can be quantified in parameters such as employment status, visits to health-care services, and use of analgesic medication (Becker et al., 1997; Turk, Rudy, & Sorkin, 1993).

The relationship between the severity of pain and the degree of disability is significant without it being a life-threatening issue, although policy makers and service planners often neglect it. This is primarily the result of the medical professions' failure to provide accurate diagnoses or intervention for relief from chronic pain. Consequently, chronic pain patients typically suffer unconditionally (Astin et al., 1996). Pain clinics are

usually considered the final option for referred patients seeking symptom relief, yet the reality indicates an insufficient number of patients are being referred (Astin et al., 1996).

The language used by patients to describe their condition should be of prime significance since it could be used as the foundation for and a preliminary step towards proper diagnosis and treatment (Sist et al., 1998). Astin et al. (1996) reported that most chronic pain participants experienced recurrent agonising pain that limited their daily mobility despite the use of medication prescribed by medical professionals, especially GPs, aiming at minimising their symptoms. Their findings suggest that the resources and care provided by medical professionals for pain relief are inadequate. Besides patients' compliance in participation, medical professionals should aim to minimise patients' disabilities resulting from chronic pain through thorough examination adopting adequate treatment intervention. White et al. (1997) proposed that highly cost-effective care that minimised suffering could result if medical professionals were better (better diagnostic criterion required) able to diagnose and treat patients prone to develop chronic pain.

### **The Link between Chronic Pain & Fibromyalgia Syndrome (FMS)**

The present investigation looks at one type of chronic pain, Fibromyalgia Syndrome (FMS), which is characterised by with widespread aching (pain) and associated symptoms and signs of a chronic pain condition. In particular, Merskey & Bogduk (1994) described FMS as, "*diffuse musculoskeletal aching and pain with multiple predictable tender points of more than three month duration*" (p. 45). FMS patients, like other chronic pain sufferers, experience day-to-day fluctuation in pain intensity and shifting in pain from one area to another is typical. The significance of FMS is its unknown aetiology and its effects on suffers as a relatively unrecognised chronic pain syndrome. In order to help shed some understanding of FMS condition, it is important to establish it amongst other conditions. As an initial step towards this, a basic understanding of chronic pain and its mechanisms is necessary for a progressive understanding of the FMS experience. Links between FMS and chronic pain will be discussed in detail in Chapter Two under the section FMS definition.

## **CONCLUSION**

Personality, physical, psychological and emotional, cognitive, and medical-care variables that influence patients' perception and severity of chronic pain were discussed. Subsequent chapters review the literature that has documented FMS discussing possible aetiology, illness perception, impact, and the coping strategies adopted by sufferers.

## CHAPTER TWO

# **FMS Syndrome (FMS): Classification, Diagnosis, Prognosis, & Symptoms**

*FIBRO=fibrous/connective tissue; MYALGIA=continuous pain*

FMS Syndrome (FMS) is common and controversial. It is a relatively newly recognised condition, despite being the most frequently observed condition in outpatient rheumatology clinics (Turk, Okifuji, Starz, & Sinclair, 1996). FMS Syndrome (FMS) is a complex, multifactorial, nonarticular, non-inflammatory rheumatological, soft-tissue condition with functional somatic symptoms. It is typically characterised by bilateral, widespread (generalised) chronic musculoskeletal, fibrous connective and soft tissue pain. FMS is not a disease (Croft, Schollum, & Silman, 1994; Schneider, 1995; Wolfe, Ross, Anderson, Russell, & Herbert, 1995; Wolfe, 1997), and in particular, it is not a “pathophysiologically defined disease” (Masi, 1994, p. 961). FMS does not have known causes, and the conditions leading to it are not well understood. Instead, FMS is a syndrome (Schneider, 1995): a specific and common set of characteristic signs and symptoms that occur together. The American College of Rheumatology (ACR) criteria indicates that FMS is a disorder of the pain system for which there is no cure. FMS may be primary, secondary to, or concomitant with another condition that causes pain or disrupts sleep. To better appreciate what FMS is, the following section will discuss the classification and definition of FMS.

### **The definition**

FMS has been known under various labels over the years, including chronic rheumatism, myofacial pain, muscular rheumatism, musculoskeletal rheumatism, psychogenic rheumatism, tension myalgia, pressure point syndrome, fibrositis, psychophysiological musculoskeletal reaction, and conversion reaction (Kahler-Hench, Miller, & Merrill, 1986; Starlanyl & Copeland, 1996). In conjunction with changes in the terminology used to describe FMS, there have been a number of developments in FMS definitions and classifications, with the first definition been offered by William Balfour in 1816. In 1990, the American College of Rheumatology (ACR) established a set of classification criteria for FMS drawn from findings of a multi-centre research project (Wallace, 1997).

These centres, that shared the same interest in FMS, conducted a joint study into the diagnosis of primary, secondary, and concomitant FMS in 1986 (Wolfe et al., 1990). Five hundred and fifty-eight consecutive patients were investigated; 293 patients had FMS and 265 acted as controls. Widespread pain, defined as “*axial plus upper and lower segment plus left- and right-sided pain*” (Wolfe et al., 1990, p. 160), was reported by 97.6% of the FMS patients. Additionally, using the criteria of widespread pain coupled with varying degrees of tenderness at 11 or more of 18 tender point, which extending over three-month duration research found a sensitivity rate of 88.4% and specificity of 81.1%.

More recently, the Second World Congress for Myofascial Pain and FMS in Copenhagen, Denmark, August 20, 1992, a consensus document that summarised FMS Syndrome (FMS) was agreed upon. FMS was clinically described as the following:

*“FMS is a painful, nonarticular condition predominantly involving muscles; it is the commonest cause of chronic, widespread musculoskeletal pain. It is typically associated with persistent fatigue, nonrefreshing sleep, and generalised stiffness. Women are affected some 10 to 20 times more often than men. FMS is often part of a wider syndrome encompassing: headaches, irritable bowel syndrome, irritable bladder, dysmenorrhea, cold sensitivity, Raynaud’s phenomenon, restless legs, atypical patterns of numbness and tingling, exercise intolerance, and complaints of weakness. A varying proportion [20-50%] of FMS patients experience significant depression or anxiety which may contribute to the severity of symptoms or result from having chronic pain. Most FMS patients experience both diurnal and seasonal variations of symptoms. Typically, symptoms are worse during periods of cold damp weather, at the beginning and end of the day and during periods of emotional stress”* (Jacobsen, Danneskiold-Samsøe, Lund, 1993).

The most recent formal classification of FMS describes it as a chronic pain condition with the code X33.X8a (Merskey & Bogduk, 1994). In this classification of chronic pain, each digit corresponds to an axis. The first digit (Axis I) concerns the regions, and in the case of FMS, X means “*to be completed individually in each case*”. The second digit (Axis II) concerns systems and 30 represents musculoskeletal system and connective tissue. The third digit (Axis III) concerns temporal characteristics of pain: pattern of occurrence and 3 represents continuous or nearly continuous, fluctuating pain.

The fourth digit (Axis IV) concerns patient's statement of intensity and time since onset of pain. Here, X represents that the time varies due to the individual case. The fifth digit (Axis V) concerns aetiology and 8 represents unknown aetiology. These digits cumulatively describe FMS as being a syndrome with unknown aetiology that is a disorder of the musculoskeletal system and connective tissue, which persists continuously or nearly continuously from the time of onset of pain. It also states that the regions of pain vary among individual cases. FMS syndrome is a chronic pain condition with no visible signs and remissions are uncommon (Merskey & Bogduk, 1994).

### **The Diagnosis**

Millions around the world are afflicted with the disorder, yet most remain undiagnosed with no visible symptoms (Smythe, Bennett, & Wolfe, 1993). In spite of the physical experience of sufferers, radiological studies (e.g. X-rays) and routine laboratory tests cannot detect it. Likewise, joint examination and muscle strength are normal. More often than not, FMS is initially mistaken as rheumatoid arthritis or another systemic arthritic condition. The key sign is the presence of pain on digital palpation (Sarnoch, Adler, & Berndt Scholz, 1997) in bilateral and multiple nonarticular tender points. Diagnosis of FMS requires the presence of 11 of 18 tender points spread over all four quadrants of the body for a duration of more than three months.

### **FMS Symptoms**

The symptom patterns of FMS have been the subject of numerous studies and reviews conducted by rheumatologists, rehabilitation professionals, and others in the healthcare community (Robins, Kirmayer, & Kapusta, 1990; Raymond & Bergland, 1994).

In addition to the typical pain symptoms, FMS sufferers also commonly experience depression, anxiety, stiffness, fatigue, sleep disturbance, and a decline in muscle functioning (Amir, Kaplan, Neumann, Sharabani, Shani, & Buskila, 1997; Kurtze, Gundersen, & Svebak, 1998). Other common symptoms include tenderness, systematic symptoms, and a range of psychophysiological comorbidities (Kurtze et al., 1998). Hudson & Pope (1989, cited in Kelley & Clifford, 1997) reported that stereotypical symptom patterns that FMS patients develop remain stable over time. These symptoms are characterised as more physically severe and debilitating, and more psychologically and emotionally complex than symptoms encountered with other chronic

pain patients (Boissevain & McCain, 1991). Symptoms can migrate and range from mild discomfort to complete debility. Investigations have revealed that FMS symptoms are continuous and prevalent (Felson & Goldenberg, 1986; Bengtsson, Backman, Lindblom, & Skogh, 1994), yet sufferers still receive information that FMS is not debilitating.

Typically, these somatic symptoms expose FMS patients to a high risk of psychological distress. Overall, FMS patients report greater pain intensity (Perry, Heller, & Levine, 1988), more depression and anxiety (Wolfe et al., 1990), more sleep disturbances and fatigue (Wolfe et al., 1990), more stressful lives (Ahles, Yunus, Riley, Bradley, & Masi, 1984), more pain-related activity limitations (Robbins et al., 1990), and greater concern with their pain (Gaston-Johansson, Gustafsson, Feldin, & Sanne, 1990) than rheumatoid arthritis patients in general. Because the pathogenesis of FMS remains ambiguous, Amir et al. (1997) concluded that its symptoms should be regarded as medically unexplained.

Many symptoms have been found to be inter-related. For instance, FMS tender-point counts have been linked to the degree of daily stress (Urrows, Affleck, Tennen, & Higgins, 1994). Croft et al. (1994) found that tender points are related to the severity of depression, fatigue, and disturbed sleep, but separate from and unrelated to pain status. Although the core symptom of FMS is diffuse musculoskeletal pain and multiple tender points, many patients present with an array of generalised somatic complaints (Bennett & Jacobson, 1994). The FMS symptoms will be introduced and discussed in more detail in Chapter Six, *The Phenomena*. Finally, the relationship between external influences (such as work-related issues) and symptoms will be explored.

### **The Prognosis**

FMS is a specific, chronic, non-degenerative, non-progressive, non-deforming, noninflammatory, identifiable, truly systematic pain condition (Starlanyl & Copeland, 1996). There is no ongoing destruction of any tissue or joint in the body. FMS does not lead to progressive deformities of the musculoskeletal system, nor does it lead to any general decline of this system. There is, however, significant fatigue, stiffness, depression, chronic muscle tension, and nervousness. Although FMS has been recognised as a coherent syndrome, much of its prognosis remains mysterious. However, (Boissevain & McCain, 1991). Masi & Yunus (1986) have outlined three potential

courses for FMS based on limited clinical data and epidemiological information from similar disorders:

- (a) *remitting-intermittent* – in which symptoms either vanish or occasionally reappear subsequent to the primary onset;
- (b) *fluctuating-continuing* – in which symptoms could intermittently alleviate but under no circumstances totally vanish; and
- (c) *progressive* – in which symptoms intensify and advance gradually.

Consistent with Masi & Yunus' (1986) proposition, Henriksson, Cundmark, & Bengtsson (1992) concluded that the FMS condition seems to be chronic and there are no reports to suggest that FMS symptoms, once established, will gradually decrease or disappear. Additionally, Masi & Yunus (1986) hypothesised that factors, including psychological operation/behaviour, location of pain, sleep patterns, duration of symptoms, and socio-economic status, could each bear on the course of FMS.

## SUMMARY

FMS has been clearly classified as a chronic pain syndrome, yet its cause remains elusive, and although prevalent, diagnosis is difficult and frequently inaccurate. Stereotypical signs and symptoms appear with the condition, which fluctuate in severity in response to one another in a cyclic fashion. As a chronic pain condition, it becomes clear that pain acts as the primary catalyst to other FMS symptoms including depression, anxiety, stiffness, fatigue, sleep disturbance, and a decline in muscle functioning. Despite being relatively obscure, the prognosis of FMS revealed a possibility of three courses in development.

## CHAPTER THREE

# **The Methodology**

### **GROUNDED THEORY**

This first section reviews the premises of grounded theory methodology as a qualitative approach for investigating complex social phenomenon. Following, the grounded theory methodology and the rationale for adopting it as a tool for a FMS study is discussed. The criteria for judging the quality of the research is mentioned, but is itemised in full in Appendix I. Finally, some disadvantages of grounded theory for the present investigation are explored.

#### **An Introduction**

Grounded theory's roots lie in sociological and social science philosophies of research. It originates from the interpretive tradition that is derived from the pragmatism and symbolic interactionism of social psychology and sociology (Corbin & Strauss, 1990; Annells, 1996; Benoliel, 1996; Wilson & Hutchinson, 1991).

Symbolic interactionism is considered the cornerstone of the grounded theory approach to data analysis (Charmaz, 1990, cited in Kearney, Murphy, & Rosenbbaum, 1994). It was between 1920 and 1950 that Dewey and Mead adopted a pragmatic, naturalistic approach to studying human behaviour (Robrecht, 1995). Blumer (1969, cited in Corbin & Strauss, 1990) later termed this *symbolic interactionism*. Symbolic interactionism is centred on "the concept of *self*" (Chenitz & Swanson, 1986, p. 5; Annells, 1996, p. 381). As an individual, human actions depend on symbols and common language, which are used to communicate (*interact*) and ascribe meaning to situations (Charmaz, 1990; Wuest, 1995; Annells, 1996). Symbolic interactionism assists the researcher to understand the practice of scrutinising participants' explanations of their own actions and contexts.

Since it originated from the tenets of symbolic interactionism, grounded theory shares with symbolic interactionism a focus on human participation and an effort to understand a situation from the participant's own perspective (Baker, Wuest, & Stern, 1992). Grounded theory attempts to discover pertinent circumstances, and how

individuals react to varying conditions and to the results of their own behaviour (Corbin & Strauss, 1990).

Two researchers, Glaser & Strauss (1967), used the term 'grounded theory' to refer to theory that is generated from the process of rigorous examination and analysis of unstructured qualitative data. Grounded theory has been designed to eliminate the fabricated objectivity and bias inherent in the positivistic, quantitative approach. It is subjective, since the conceptual theoretical framework is developed from data and is influenced by investigators' and participants' experiences in their own lives (Keddy, Sims, & Stern, 1996). The goal is to establish intersubjective meaning or *Verstehen* (Henwood & Pidgeon, 1994, p. 229) from the interdependent relationships between investigators and participants about the participants' domains.

The objective of grounded theory is theory development – *theoretical conceptualisation* (Strauss & Corbin, 1994) or conceptual framework – through generating theoretical constructs and identifying core variable(s) or process(es) from social circumstances. These core constructs explicate basic characteristics, patterns and problems in the naturalistic context under scrutiny, known as the "basic social-psychological processes" (BSPs) (Glaser, 1978, p.102). BSPs represent the most central or problematic factor(s) for participants experiencing the investigated phenomenon (Glaser, 1978). They justify changes in interaction with a phenomenon, behaviour, or problems inherent in various groups over time. The aim of grounded theory methodology is to generate substantive grounded theory and discover dominant structural processes about social, sociological, and psychological phenomena at a high level of abstraction at both the symbolic and interactional levels (Chenitz & Swanson, 1986; Wilson & Hutchinson, 1991; Wuest, 1995).

### **Rationale for Using A Grounded Theory Methodology**

Any health professional who has tried to use the results of social scientific research to guide the planning or evaluation of health promotion programmes is aware of the limitations of both qualitative and quantitative approaches (Buchanan, 1992). On one hand, quantitative (positivist) approaches emphasise the methodological precision of operationalisation and measurement with results that are often seem shallow, abstract and meaningless in the real world. In aiming for a parsimonious explanatory model, quantitative researchers try to identify independent variables that are generalisable to the

population as a whole. These variables have been found to correlate with an dependent variable of interest in sample populations that may differ by socio-economic status, race, gender, age, religion, and so on. It is not surprising, therefore, that many factors that hold up are both banal and not particularly powerful predictors of behaviour. On the other hand, qualitative research is regarded as an exploratory, descriptive, or hypothesis-generating methodology (Buchanan, 1992). In an effort to provide in-depth, rich descriptions, qualitative researchers rely on a relatively small number of case studies. The results of qualitative research almost invariably raise questions about its objectivity and representativeness, although they are often more meaningful to the sample population.

The present research sought to gain a novel perspective of the FMS condition from the personal experience of patients using the interpretive approach of grounded theory. Literature revealed that research using qualitative procedures is considered most useful to gain a fresh point of view on human health (Baker et al., 1992; Cheek, 1996). The interpretive approach views individuals as active agents, who interact with others to co-create the meaning of their experiential world (Neimeyer, 1993). Charmaz (1990) noted that grounded theory methodology is useful for studying the experiences of chronic illness through interpretive analysis. Specifically, grounded theory methodology allows the generation of inductive theoretical explanations of psychosocial data from sociological reality (Baker & Stern, 1993). The current study on FMS is an area of health psychology where theoretical explanations need to be developed.

Professionals and participants can use the developed substantive theory to aid comprehension and intervention into FMS, as well as a basis for further quantitative research (Olshansky, 1996). From the patient's perspective, the value of interpretative social science comes from its ability to aid sufferers in improving their own skills of autonomy and independence. For the health professional, results will assist in the advancement of new health practices and people-oriented care for FMS suffers. In other words, a theoretical account of the FMS phenomenon provides a basis for discussion to implement change. For the researcher, the most compelling reasons for using grounded theory in an investigation of FMS are to gain insight into aspects of an under researched phenomenon, from an original perspective (Stern, 1980). Theoretical frameworks, which promote understanding need to be identified under any circumstances, particularly when one attempts to scrutinise complex areas of behaviour, while new perspectives contribute significantly to empirical issues. A theoretical account of FMS will enable the

investigator to question the similarities and differences between the emergent theory and other theories in the relevant field, especially regarding goodness of fit (reliability), and scope of coverage (Martin & Turner, 1987).

In summary, the use of grounded theory methodology in a study FMS provides the researcher the tools to concentrate on and conceptually interpret meaningful discourse data. The strength of patient accounts lies in their ability to give health psychologists an understanding of the experience of FMS.

### **Disadvantages of the Qualitative Approach**

Recognising the disadvantages of the qualitative approach adopted in this research is mandatory. Interpretation is the core issue of qualitative research. Seeing participants' worldviews through their eyes should be viewed as a questionable, complex exercise regardless of the researchers' understanding and interpretation of the participants' domain (Bryman, 1988). A number of disadvantages arise given the reliance on the seemingly subjective view of the interviewee. For instance, the reliance on language as the tool for comprehension is a potential weakness. The way language is used and the difference between '*what is said*' and '*what is meant*' is a disruptive factor of the qualitative approach. This is particularly true when the researcher and participant are of different gender, ethnic background, or religion. Verbalisation as the dominant aspect of daily communication presents challenges to interpretation through the conflicts between verbal and non-verbal communication (i.e. gesticulation, facial expressions, posture) (Jaeger & Rosnow, 1988). The critical issue here is that the '*meant*' meaning needs to be carefully and precisely negotiated between the researcher and participants if interpretation is to have any validity.

There are several potentially common pitfalls or weaknesses for researchers who adopt grounded theory methodology. Firstly, researchers should be cautious of reporting long verbatim biographical narrative or descriptive findings. One needs to ask oneself "what is going on and how", which provides answer for conceptual explanations of a social phenomenon.

Furthermore, caution needs to be exercised against the generational error that occurs with mixed or muddled qualitative methods (Wilson & Hutchinson, 1996). To protect against this, researcher should avoid deviating from the criteria of grounded theory (Becker, 1993; Wilson & Hutchinson, 1996).

In terms of the process of analysis several issues become salient. One major drawback is the researcher's susceptibility to only analysing data at the conclusion of data collection, which goes against the grounded theory premise of simultaneous data collection, coding, and analysis. As such any emergent theory must result from a constant reciprocation between data, conceptualisation, and further data collection.

Inductive positivism, premature closure and commitment to categories by the researcher who has not properly scrutinised or has under-analysed the meaning of narrative data is a common error (Charmaz, 1990; Wilson & Hutchinson, 1996; Stanley & Wise, 1983). To counter this, a researcher should strive for intellectual thoroughness by constantly questioning data in a continuous process of strategic and logical reasoning. Sensitivity to cues and insinuated norms and the ability to discover patterns rooted in apparently irrelevant incidences are mandatory for comprehension of meaning embedded in qualitative data.

Another issue to grounded theorists is a risk of importing concepts (intentionally or unintentionally) when they do not withdraw themselves from preconceptions, disciplinary perspectives, and empirical readings during data analysis (Wilson & Hutchinson, 1996). Such a shortcoming will lead to a failing to establish a truly novel, grounded theory.

Further, Leininger (1992) has pointed out the scarcity of competent or qualified mentors and researchers to guide apprentice researchers through the grounded theory methodology. The researcher of the current study consulted her primary and secondary supervisors because of their individual specialities in pain research and grounded theory methodology respectively for rigorous guidance.

Finally, on potential disadvantage of grounded theory is that it will be judged by quantitative criteria for a good research. It is necessary to specify the criteria by which a qualitative research should be judged, since criteria for appraising the quality of psychological research from the positivist paradigm have been limited to positivist methodologies and are, therefore, improper for grounded theory. Appropriate criteria for grounded theory have been included in Appendix I to address this potential disadvantage.

## **THE PRESENT STUDY**

This part of the investigation reviews the aims and assumptions of the investigation. Following the method of data collection and the development of the interview questions is discussed. The next part describes the procedure, participants' profiles and their FMS histories. Finally, the method of data analysis is reviewed together with the rationale and method of transcription, and the paradigm model that guided data coding.

### **Aim**

The primary aim of the present research was to investigate patients' perspectives on the FMS experience. A second aim was to identify the aetiology and symptoms of FMS from patients' perspective. Although the aetiology and symptoms have been identified for FMS from a clinical perspective, little has been done from patients' perspectives. The third aim of this investigation was to identify the impacts and consequences of FMS from patients' perspective, and to find the spontaneous coping strategies they adopted and developed since its onset. Finally, the study attempts to explore factors external to FMS patients that seem to inhibit and/or enhance their response to the condition.

### **Prior Assumptions**

The researcher, as a socially active and culturally shaped 'being', possesses a depth of knowledge and personal experience, which inherently leads to a subjective bias in the formation, analysis, and discussion of the research. To acknowledge the lack of impartiality it is necessary to identify the theoretical sensitivity of the researcher. A researcher must therefore acknowledge the assumptions and expectations with which they enter the field of investigation. The present researcher entered the research of the patients' perspective of FMS with the following assumptions. These are the combined result of a literature review and reflection on personal feelings that arose out of interviews conducted with FMS sufferers.

- I assumed that a common/shared perspective on the FMS phenomenon would emerge from individual experiences of living with FMS.
- I assumed that the aetiology and symptoms of FMS for the present diagnosed patients would closely parallel those of clinical studies, but that personal experience would provide greater sensitivity to exploring the FMS phenomenon.

- Because FMS is defined as a diffuse musculoskeletal chronic pain syndrome with multiple tender points (Wolfe et al., 1990), I assumed that pain would represent a highly salient aspect of the FMS experience. However, I was careful not to let the literature colour the interpretation of the emergent theory.
- I assumed that a pattern of consequences and coping strategies would be revealed from the interviews with FMS patients. I further assumed that patients would progress through an evolutionary sequence of consequences and coping strategies based on their growing experience with the condition. Given the small population of New Zealand, the relatively small number of accurately diagnosed FMS sufferers, and the lack of research, I felt that patients taking part in the study would share a high degree of commonality in their experiences of FMS.
- I also assumed that external factors would enhance or inhibit FMS sufferers' responses to the condition in the form of intervening conditions. This assumption was based on trends from the literature and reports of sufferers' of similar chronic pain conditions.
- The assumption that a grounded theory methodology would be most suitable for researching the FMS phenomenon from patients' perspective was based on the literature. As stated by Sist et al. (1998) and Astin et al. (1996), the language patients use to describe their conditions is of prime significance since it can be used as the foundation for improving diagnosis and treatments.
- Furthermore, because the study is concerned with the interpretation of situations and their meaning to participants, the grounded theory methodology was assumed the most suitable methodology. This is was due to the fact that grounded theory is concerned with the interpretation of unfamiliar patterns of human communication and the meaning ascribed to them since so little of The phenomena and the patients' experience of FMS is known. Moreover, the suitability of the ground theory approach arose from the need to use a method that helped the researcher to scrutinise the patients' explanation of their own situations, actions and experiences.

## **METHODOLOGY FOR DATA COLLECTION**

### **The Interview**

Grounded theory methodology was selected for this study to analyse interview transcriptions. Thus, the approach was used to discover an emergent theory from textual data (Kearney et al., 1994). The purpose of a formal, qualitative interview is to obtain verbal information from participants and gather descriptions of situations in detail (Lofland, 1971). Questions covered five broad categories relevant to FMS from the patients' perspective: causation, symptoms, personal feelings, effects, and coping. An informal conversational setting could be maintained since there was no specific sequence for asking the interview questions. However, when the opportunity arose from natural breaks, pauses, and changes in sub-topics, the researcher would ask a new and currently relevant question to maintain the rhythm and flow, and to ensure all questions were covered prior to the conclusion of the interview. An open-ended, in-depth, unstructured interview schedule was selected for the interviews, as the best approach for eliciting participants' personal and private concerns through everyday mundane discourses (Glaser & Strauss, 1976). A copy of the questions that guided the interview can be found in Appendix II. The informal interview has the advantage of generating natural speech and interactions between the researcher and the participant. Informal interviews also have the flexibility to allow the researcher to manoeuvre the conversation onto selected topics in a social manner customary (and therefore comfortable) to participants. The interview technique ensured interviewees' credibility and prevented distortion and prejudice to subjects' responses (Corbin & Strauss, 1990).

Prior to the interviews, the content and structure of the questions were reviewed with a senior lecturer in health psychology, who was also the primary research supervisor. One pilot interview was conducted with a FMS patient to test and further develop and refine the content of the interview.

Previous research has suggested recorded tapes of individual participants should be transcribed and subjected to preliminary analysis immediately following the interview or prior to the subsequent interviews in order to enhance researcher interpretation enhanced through recall of the interview (Swanson, 1986). Additionally, to prevent an overload of data collection, an interview schedule of no more than two interviews per day has been recommended (Swanson, 1986). One interview per day was organised for

the current research because the duration of the interviews and to allow the researcher to transcribe the data immediately after each interview.

Interview content is not standardised but varies according to the emerging theory and stage of data analysis (Glaser & Strauss, 1976). Therefore, central content areas (ie., causation, symptoms, coping strategies, consequences) identified and followed up during the data collection may not have been addressed by earlier respondents, leading to the possibility that only a small number of participants actually addressed the issues in question. To check retrospectively the degree of support for the core theory across the sample, the researcher returned to all interviewed data to determine how many participants had spontaneously described each element relevant to the paradigm model of FMS.

### **Developing Interview Questions**

The following guidelines were used to develop interview questions.

The course of interview should be in the form of “direct conversation” as Lofland & Lofland (1995) suggested. Participants’ current physical and psychological condition, the relationships established between researcher and participant, researcher’s conceptual theoretical perspective, and the topic are some of the directional determinants of interview conversation. An overly directive researcher risks intercepting potentially valuable information and offending chronically ill participants by unconsciously embedding personal assumptions in the questions. The risk of this was reduced by the use of open questions, such as “How did you end up having the treatment?”

Interview questions can be categorised into short face-sheet, informational, reflective, emotionally oriented, and ending questions. These question types provided a basic structure and order for participant interviews (Charmaz, 1990). Neutral, factual, and compulsory information characterise short face-sheet questions. Participants from this study completed a face sheet (Appendix III), which consisted of short questions of demographic details. This information helped to familiarise the researcher with the participants for the subsequent interviews.

The informational questions collected data on personal history, types of events, degrees of awareness, types and cohorts of participants, and so on. Such questions serve as a bridge to create trust and rapport that allows the researcher to address reflective and emotional questions.

The transitional characteristic of reflective questions allows the researcher to question participants in a straightforward manner about personal topics focusing on individual participants and significant others: “What are your experiences of FMS?”; “How has FMS affected you?”; “How would you compare the person you are now to before having FMS?”; “What do you think of the way your family/friends/colleagues have responded to your FMS diagnosis?”; What coping mechanisms have you found useful, and how are you able to find and use their strengths?; and so on.

The researcher should ask emotionally-oriented questions to gather relevant data about participants and their social networks: “How did you react/feel when you first heard of your FMS diagnosis?”; “How did you feel about being unable to work (or work full-time)?”; “How has ongoing pain affected your personal, interpersonal, and social lives?” Reflective and emotionally-oriented questions have the shared objective of assisting the researcher to obtain the narrative from individual participant’s account while minimising the researcher’s interference and fabrication (*demand bias*) (Mishler, 1986).

Researchers attempted to finish the interview with ending questions that allowed participants to leave with a sense of the value in terms of participation. The more intense the interview, the more feedback is needed to end the interview with the subjects feeling positive about themselves. Questions like “What have you learned about yourself over the past years/months?”; “How have you grown as a person after having these experiences?”; or “What are your future prospects regarding FMS?” – can elicit interesting data with insightful, symbolic meanings of illness and self and help to accomplish positive closure. In addition, the researcher of present study tried to complete the interviews in a casual conversational manner that reflected typical subjects’ daily forms of interaction, and the researcher offered her thanks for the subjects’ participation.

## **Participants**

Eight participants, aged from 16 to 51 years, with a mean of 37.125 years, were interviewed. Educational levels for the entire sample ranged from secondary school at the lower end of the scale to tertiary level diplomas at the higher end. All participants had been formally diagnosed with FMS syndrome, with their condition duration ranging from one month to nine years. Seven of the participants were female and one was male.

The sample was predominately Pakeha. There were two Maori, but both preferred to identify themselves as New Zealanders in general.

A non-probability and theoretical sampling procedure was adopted because the developing analysis and conceptual frameworks direct the selection of data in terms of units and typologies (Baker, Wuest, & Stern, 1992). In this study, the researcher undertook sampling by conducting interviews with participants individually. Eligibility for participation in interviews required that subjects were diagnosed with FMS. Respondents outside the Palmerston North region were excluded prior to interviewing for the practical reasons of inconvenience of travel, research budget constraints, and potential unnecessary pain associated with long-distance travelling for the participants. All respondents who were excluded from participation in this study were given an explanation and were offered a summary report of the study upon completion.

### **Profiles and FMS history of Participants**

This section gives a brief demographic description of the individual participants. The medical diagnoses and participants' history of pain are outlined. Their reactions to the interview are noted. Participants were allocated code numbers to ensure confidentiality.

P1 is a female, aged 36 years. She was single at the time of the investigation, but had been married. She is of European and Maori decent, and has lived her entire life in New Zealand. Her main source of income was government assistance – Domestic Purposes Benefit (DPB) – and part-time work. She had attended school up until secondary school (fourth form level) with some later part-time studies as an adult student. P1 comes from a dysfunctional family environment with insufficient parental guidance and apparently poor nutrition. P1 feels psychologically traumatised, and physically impaired with a weak frame and an extremely low tolerance for pain. Although suffering from groin pain and having consulted various medical-care specialists over the last five years, it was not until recently that she was diagnosed with FMS. P1 was enthusiastic and self-confident throughout the interview. She provided numerous in-depth accounts of her medical history and experience with FMS, and expressed a desire to increase her awareness of the condition.

P2 is a female, aged 34 years. She was single at the time of the investigation and has never been married. Her main source of income was government assistance – DPB. When she was interviewed, she was involved in voluntary work and actively seeking a

part-time job. She had attended a polytechnic course in typing and office assistance. Although P2 has suffered from physical discomfort for the last ten years and consulted various medical practitioners, it was not until 1998 that she was diagnosed with FMS. During the past ten-year period, P2 was particularly prone to wrist and neck injuries, which resulted in frequent medical visits. P2 was interested in the research, but showed little enthusiasm during the interview and towards the interview questions.

P3 is a female, aged 16 years old. She was single at the time of investigation and has never been married. Living at home, P3 was solely supported by her parents. At the time of the interview, P3 was attending secondary school and mentioned an intention to attend a tertiary institution. P3 was diagnosed with FMS in June 1998, but had suffered from continuous and increasing pain and other FMS-relevant symptoms since a work-related injury in July 1997. She believed herself to have a better understanding of FMS condition than the medical practitioners she had dealt with. P3 expressed her concern about FMS and excitement about FMS research during the interview.

P4 is a female, aged 42 years. She was married at the time of interview. P4 was unemployed as a result of her physical state at the time of investigation. She attended Teachers' College and had taken tertiary courses towards a Bachelor of Arts degree. She was diagnosed with FMS in late 1997 and she believed that she had symptoms since a neck problem began approximately three years earlier. P4 believed that a back injury from a car accident in 1978 contributed to the neck pain. P4 showed great enthusiasm towards the topic and provided in-depth personal beliefs about the condition.

P5 is a female, aged 26 years. She was single at the time of investigation and had never been married. P5 held a diploma in Tourism and Office Systems with a major in Japanese. She intended to further her tertiary education with full-time study in either osteopathy or business while in New Zealand. P5 was diagnosed with FMS five to six years prior to 1998 by a rheumatologist. P5 has had problems with her neck since she was 10 years old, when she fell from a handstand. In addition, she has always had a tendency to injuring of her joints. As a precaution against headaches, P5 carried Panadol or Nurofen in her handbag since the age 12 or 13 years. Because of her condition, P5 is typically a light sleeper, who described needing 10 or more hours of sleep a day in order to cope with severe fatigue. She has had allergies like hay fever and dermatitis, and a frequently upset stomach since she was about 14 years old. Although she was diagnosed with FMS, P5 had minimal information about her condition and has ignored it as a way

of coping. P5's participation in the interview was motivated out of hope to learn more about FMS.

P6 is a female, aged 51 years. She was in her second marriage and was unemployed at the time of investigation. Her main source of income was the invalid benefit. P6 possessed a high-school qualification. She was diagnosed with FMS approximately eight years ago, although she has had ongoing problems with her knee and hands. This was aggravated when she had a serious nervous breakdown due to a marriage failure 12 years ago. P6 suffers from severe arthritis of her hands, hernia, and high blood pressure. As a result of unsuccessful experiences with medical-care practitioners, P6 does not tolerate being touched by physiotherapists and has been solely dependent on medication. P6's FMS condition has improved significantly since the diagnosis with the help of medication and lifestyle change. Both P6 and her mother participated in the interview open-mindedly and provided in-depth information relevant to the investigated field.

P7 is a male, aged 50 years. He was the only male participant in this research and was married at the time of investigation. His main source of income was part-time work as a prison officer, although he has planned to work full-time once he is declared fit by his orthopaedic surgeon. He attended school up until fifth form and has no formal qualifications. P7 was diagnosed with FMS early in July 1998, although he believed he gradually developed FMS symptoms and has had increasing pain from an operated knee since January 1997. He has had 14 or 15 operations on his knee and the last operation had an aversive effect on him both physically and emotionally. P7 expressed great interest towards the topic. He provided a briefly dated summary of his medical history and experience with FMS.

P8 is a female, aged 42 years. She was married and worked part-time as a home helper at the time of investigation. Her income was from her part-time job and a small disability allowance. P8 had attended school up until fifth form level. She was diagnosed with FMS in April 1998, but believed that she developed symptoms (i.e. constant headache, pain) after a work-related injury eight years earlier. P8 reported that she suffered tremendously both psychologically and physically. She has developed a pessimistic attitude towards medical practitioners because of numerous unsuccessful consultations. P8 was rather pessimistic and emotional throughout this interview, perhaps due to her feeling vulnerable and mistrustful, particularly of mental health-care practitioners.

## **Procedure**

Participants were recruited through a local newspaper advertisement in Palmerston North (Appendix IV). Participants were asked to leave their names and contact phone numbers on an answer-phone. Respondents were telephoned and a brief outline of the study was provided. If they met the research criterion and were prepared to participate, a time and date of the interview were negotiated. Information sheets were then mailed to the participants. Participants were asked to complete an informed consent form, which included agreement to participate and permission for the tape recording of the interview. A copy of the information sheet and consent form is attached in Appendix V and Appendix VI. Confidentiality was assured verbally and in writing. All interviews were conducted in the Massey University, Psychology Clinic's private interview-rooms. Due to the symptomology of FMS, participants were encouraged to take breaks or move around during the interview if required.

The researcher conducted all of the interviews, which lasted from 1 to 2.5 hours. The interviews were guided by a set of initial semi-structured questions and proceeded with as little interpolation by the interviewer as possible. Non-directive probes were used to maintain the flow of the interview. Directive probes were used as circumstances required. A paramount consideration was that the participants felt content with themselves that they had made a significant contribution to the knowledge of pain management, and that the research process could somehow improve their self-esteem. Therefore, participants were consulted as subject matter experts (SMEs) throughout the interview and their ability to pass on valuable information was affirmed.

Several months later, all the participants and other respondents received a Summary of Findings letter (Appendix VII). The summary outlined the general findings and summarised the emergent theory in a way participants would understand.

## **METHODOLOGY FOR DATA ANALYSIS**

### **Transcription**

Tapes of the interviews were transcribed in order to code data according to the paradigm model. Moreover, through the process of transcription and its opportunity for repetitive and careful review of the recorded interviews, the researcher was able to reflect on the meant and intended meaning of the interviewees' verbal responses. In other words, the

transcription itself represented an initial step in analysis that allowed the “subjective meaning” of the data to emerge. This initial emergence was achieved through the inherent capacity of transcription to demand that the researcher closely and accurately scrutinise the participants’ responses. Through the transcription, the researcher gained familiarity with the data, familiarity that later served as a basis in subsequent coding and analysis.

In terms of the actual process, all interviews were transcribed in full text by the researcher who listened to the taped data repeatedly to extract distinguishing words, phrases, or sentences and vocal expressions, which were later printed in capital letters. Facial expressions and body language were observed and described in footnotes to assist data analysis.

### **Coding**

Transcriptions were coded using traditional manual method. This was selected in preference to computer software packages such as NUDIST based on the premise that data analysis in grounded theory using computer programme is inflexible and subject to the pre-set condition of the software that identifies the core variables (Becker, 1993). Because of the inflexibility and incapacity of the software to process the finer complexities of communication, there is a real danger of imposing categories where none exists. Further, the potential to impose categories undermines the objective of grounded theory, which strives for emergence in theory development. Although technology is rapidly improving, computers remain a long way from ‘understanding the meaning’ embedded in social interactions. Typically, results derived from computer analysis can be monotonous and oversimplified. Therefore, the researcher in this study analysed the data manually to circumvent this possibility

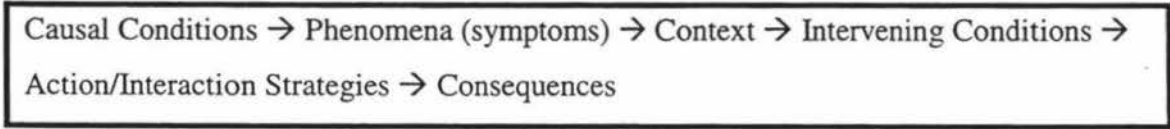
Data collection and data analysis in grounded theory are interrelated processes (Corbin & Strauss, 1990) and thus were implemented concurrently while retaining their systematic and sequential characteristics. The researcher’s responsibility in conducting grounded theory research is to remain open to what is actually happening (Glaser, 1978). Through the application of constant comparative method, the researcher was able to consider all potentially relevant aspects of the data from various emergent perspectives. This guided the discovery of emergent theory in a controlled and systematic manner on the basis of an established grounding in the reality of participants (Glaser & Strauss,

1967). Three levels of coding and memoing were used to assist the progress of decision-making for theoretical sampling (Wilson & Hutchinson, 1991). Each concept discovered and introduced into the study during the research process was initially considered temporary. Concepts became permanently integrated into the theory through either their recurrent presence in interviews or significant absence. Grounding concepts in the reality of data gives this method theory-observation congruence and compatibility (Corbin & Strauss, 1990).

In order to develop an emergent conceptual framework from the experiences of FMS suffers’ with the capacity to capture emergent ‘cause and effect’ relationships from social phenomenon, the present study adopted the paradigm model of Strauss & Corbin (1990).

**The Paradigm Model**

In grounded theory, the paradigm model (Glaser, 1992; Strauss & Corbin, 1990) is a tool for data analysis which emphasises cause and effect along with other stimuli (i.e. phenomena, context, intervening conditions, and action/interaction strategies) that are central to the coding process in the research objective of FMS. A paradigm model assists the researcher in analysing data systematically. By using this model, the researcher can analyse associating categories, subcategories, and concepts in relatively complex ways necessary for generating a conceptually and theoretically dense framework. The paradigm model functions as a prompt for coding data according to relevance, irrespective of the phenomena referenced by a given category. The following is a simplified paradigm model:



**Fig. 3. The paradigm model**

The causal (or antecedent) conditions refer to events or incidents that FMS patients believe have lead to the occurrence or development of a phenomenon (Strauss & Corbin, 1990). These incidences can cause or bring about the pain experience. For instance, FMS test cues could include references such as “when”, “while”, “because”, “since”, “as”, “due to” or “on account of”. In congruence with the multifactorial

causation of FMS, any singular causal condition lacks explanatory power of *The phenomena*.

A phenomenon represents the central idea, event, occurrence about which a set of action/interactions are aimed at managing, handling, or to which the set is related (Strauss & Corbin, 1990). Phenomena under this particular circumstance are synonymous with FMS symptoms.

Context represents the specific set of properties that apply to a phenomenon, namely, the location of incidents relevant to a phenomenon along a dimensional range (Strauss & Corbin, 1990). Concurrently, context serves as a particular set of circumstances within which the action/interaction strategies are accomplished, and how they manipulate and react to a specific phenomenon (Strauss & Corbin, 1990).

Intervening conditions come between cause and effect and serve to either restrain or assist the action/interaction strategies within a specific context (Strauss & Corbin, 1990). Intervening conditions act as the broader structural conditions affecting action/interaction strategies. These conditions comprise time, space, culture, economic status, technological status, career, history, and individual biography, and so on.

Grounded theory methodology is characterised as a theory-building approach that is action/interaction-oriented. Therefore, action/interaction focuses on coping, managing manipulating, and responding to a phenomenon as it exists in context or under a specific set of perceived conditions (Strauss & Corbin, 1990). The interactional element identifies self and other interaction. Action/interaction strategies are purposive behaviours performed by patients and medical professionals with the intent of bringing about positive change for the patient afflicted by FMS. There are four properties in action/interaction strategy research:

- (1) It is processed naturally and can be studied in sequences, movement, or change over time.
- (2) It is purposeful or goal-oriented – it is used in response to or to manage a phenomenon, which then occurs through strategies and tactics.
- (3) It is equally significant to identify failed action/interaction.
- (4) There are always intervening conditions that either assist or restrain action/interaction.

Regardless of whether action/interaction strategies are taken to manage or respond to a phenomenon, they have certain outcomes or consequences and these may not always be what was anticipated or aimed for. Consequences can be detected by cues

in participant dialogues such as “the result was”, “the consequence was”, and “in consequence”.

### **Open Coding**

The analysis process began with open coding, which ‘fractured’ the data into concepts that could be labelled and sorted while remaining ‘open’ or unrestricted by predetermined theory. This interpretive and first step of theoretical analysis was unobstructed by analytical coding involving fracturing of the data, that is, “word by word and line by line” (Strauss, 1987, p. 28). The objective of open coding was to develop temporary concepts that seemed to fit the raw data. This was achieved through a constant comparative method (Strauss & Corbin, 1990, cited in Kearney et al., 1994) That is, the researcher compared incidents/interactions to other incidents/interactions for similarities and differences. The data were examined for regularity and for an understanding of where that regularity was not apparent. Finding patterns or regularities helped to give order to the data and assist with integration (Corbin & Strauss, 1990). Reasons for differences were pursued. Similar incidents were then named using titles from the interview transcripts and conceptual labels to form categories and/or subcategories due to their shared conceptuality. Two questions were asked when labelling the incidents: *What is this? What does it represent?* (Strauss & Corbin, 1990). These conceptual labels were usually words and/or phrases used by informants – FMS patients – themselves, known as “*in vivo*” codes (Glaser, 1978, p. 70; Strauss, 1987, p. 33). These codes symbolised conceptual or substantive definitions of what appeared in the data. The resultant codes were labelled as substantive codes. Individual interview data were first coded separately and consequently a separate list of substantive codes emerged. The smaller fractions of codes, properties and dimensions, were identified for re-categorisation as part of the next step of coding.

Open coding and a constant comparative method both have the benefits of protecting the research from researcher subjectivity and bias, as well as accomplishing greater precision and consistency by providing an innovative way of explaining phenomena exhibited in the data. Precision can be improved through the comparison method, which prompts further partitioning of the initial conceptual framework resulting in different concepts or variations from the original framework (Corbin & Strauss, 1990). The generative and comparative questions then guided the researcher returning to the field or data.

### **Axial Coding**

Data was reconstructed in new ways during the axial coding process. Relationships were made between categories, and categories and their subcategories, which shared homogeneous properties. These relationships were verified by scrutinising existent data. The objective of axial coding was accomplished through the use of the “paradigm model” (Strauss & Corbin, 1990), which allowed the merging of subcategories that related to categories. The paradigm model consisted of causal conditions and the context relevant to FMS, and intervening conditions, which either constrain or facilitate the conditions of FMS. The paradigm model also adopted action/interaction strategies, the action/interaction strategies FMS patients adopted to respond to, manage, improve FMS symptoms, and the consequences of FMS. In the current study, categories were provisionally related through their position in the paradigm model or their relationships with each other as antecedents/precursors or consequences. Theoretical interaction began to emerge, which, in turn, allowed a basis for further exploration once relationships between categories were established (Glaser, 1992). Finally, any hypothetical relationships, which arose deductively during axial coding were regarded as temporary until verified repeatedly against new data.

### **Selective Coding**

Selective coding involved a process of systematically consolidating all categories around a core category. At this stage, the researcher terminated the open coding procedure and demarcated codes to categories relevant to the core category. The core category serves as a guide for further theoretical sampling and data collection. The core category can be any theoretical code such as cause or condition, or consequence from any family of theoretical codes such as processes or strategies (Fagerhaugh, 1986). The emergent core category represents the principal phenomenon of the study and therefore must be a phenomenon that was reflected repeatedly within the data as well as a universal theme of all categories. This central phenomenon emerged as being both a condition (i.e., symptom) and a consequence of FMS patients’ adopted coping strategies (Strauss & Corbin, 1990).

The axial codes were further merged into a more abstract level of analysis – selective codes – with analogous general codes used in axial coding, referred to as the *six C’s* (Glaser, 1978): causes; contexts; contingencies; consequences; covariances; and

conditions. The *six C's* were the properties the axial codes compared with each other to integrate them into selective codes. The use of these properties served as the foundation for scrutinising and defining the relationships within, between, and among the axial codes, selective codes, and the core category.

The identification of the core category is crucial for integration of data since it justifies most of the variation within a pattern of functions. The core category is held responsible for developing emergent theory with its *integration, density, saturation, completeness, and delimiting focus* (Glaser, 1992, p. 74). The core category was identified through the following questions (Corbin & Strauss, 1990):

- *What is the primary analytic concept presented in this research?*
- *What would be included if my results are to be theorised in few sentences?*
- *What are all the action/interaction strategies about?*
- *What are the interpretations for the variation between and among categories?*

The core category could have emerged from among the already existent categories, or a more conceptual terminology might have been required to interpret the main phenomenon. Diagramming was adopted to assist the integration of categories. The continuous reciprocity between generating theoretical analysis and confirmation with data developed the emergent conceptual framework. Interview transcripts and segmented data were revised with comprehensively.

There was no linear association between these codes and the core category, which serves to integrate the entire data. The substantive, axial, and selective codes of all eight interview transcripts, interpretations, and overall integration of data was reviewed by a supervisor until a consensus was achieved.

## **AN EXPLANATION FOR THE THESIS STRUCTURE**

Because this investigation took a global perspective on the patients' FMS experience in the real world, it became impossible to filter findings into their purest form without compromising the semantic integrity of the study. That is, to separate a section of dialogue to its purest form would result in the loss of context, which provides the background meaning that helps shaping one's understanding of the piece of discourse. Moreover, isolating findings into discrete components would take away from the aim of

the investigation, which sought to reveal the central phenomenon of the FMS experience. Consequently, the study presents much of the data in an integrated manner that reflects the true nature of dialogue in which it was presented. Because of the complexity and relationships that exist between concepts in the data, a system of cross reference (**CR**) was devised to allow the reader to view the 'whole' of FMS experience through many relationships between different pieces of data in the investigation.

From a pragmatic position, the integration of data analysis, literature, and, to some degree, discussion was necessary in order to reduce the demands on the reader which would have occurred using a traditional report format. Specifically, the complexity and inter-relatedness between concepts was such that each needs to be analysed and discussed sequentially in order to appreciate the FMS experience as both a whole and according to the divisions subscribed by the paradigm model. Moreover, the present format was designed to reduce the overall size of the written report by eliminating the need to restate information. Therefore, the format should allow the reader to transverse easily and quickly from relevant literature to the supporting data and discussion.

## SUMMARY

This chapter has given the justifications for adopting a grounded theory methodology and has acknowledged both the advantages and disadvantages. The use of the present methodology was based on its ability to represent reality through FMS patients' perspective, exploring the contexts of FMS patients' use of coping strategies, and serving their interests as research participants. The lack of theory in the areas of FMS aetiology, intervening variables, patients' coping strategies, and consequences were additional reasons since there is a need to generate emergent theory from qualitative data. Criteria for assessing the quality of qualitative and grounded theory research was also introduced.

The aim of the study has been reviewed and the methodology for data collection and data analysis has been described. The profile of FMS participants, their demographic details, their histories of medical condition and pain, and their responses to the interview were detailed. Subsequent chapters describe the emergent theory, the integration of data and the descriptive detail that supports the emergent theory.

## CHAPTER FOUR

# **The Core Category: Living with Chronic Pain**

## **CONCEPTUAL ANALYSIS**

The aim of grounded theory approach is to explain and synthesise a chosen psychosocial context by specifying a relevant theoretical core and subsidiary categories or procedures from data. This theoretical core, or core category, serves as the “fundamental canon” (Charmaz, 1990), which identifies what is happening in the context and guides the analysis. This chapter begins by discussing the conceptual analysis that draws together all of the data. The conceptual analysis will be supported by an in-depth description and explanation in subsequent chapters. Although this is the reverse order in which the data was inductively analysed, it allows the reader to appreciate the direction of the investigation.

Pain was frequently described by all participants during each interview and subsequently became the starting point for the substantive code during the open-coding stage of data analysis. Pain originated as one of the FMS symptoms and was sub-categorised into sites, duration, severity, and patients’ descriptions of pain. The pain experienced by FMS patients was described as a two dimensional code, with a concurrent identifiable localisation of pain to specific anatomical structures and a more generalised notion of pain to all body structures and systems. The specific pain sites were further dimensionalised into facial, neck and shoulder, trunk, and the extremities. Generalised pain was described as “all over” the body by FMS patients. Apart from pain locations, the type of pain emerged from each part of the body system, which consisted of dimensions of skeletal, visceral system, striated muscles, respirator, soft tissue sensitivity, and central and peripheral nerve systems. All patients described these problematic symptoms with relevance of pain descriptions.

All participants described a direct association between their experience of FMS conditions and pain since their diagnosis. The pain symptom activated and aggravated an increasingly severe cycle amongst various other symptoms of FMS, which subsequently underlined changes in lifestyle and work habits as well as behavioural and social activities for all FMS patients. Pain was reported to have directly caused a decline in FMS patients’ immune and circulatory systems, while concurrently affecting FMS patients’ cognitive wellbeing. There were direct, reciprocal effects and inverse relationships between pain and

quality of sleep, psychological wellbeing, and patients' energy reserves. Sleep disturbance was associated with a decline in energy reserves, which then affected an individual's psychological wellbeing and cognitive functioning. A by-product of this was an increase in system pain, including the visceral system, striated muscles, respirator, central and peripheral nerve systems. Sleep disturbance was linked to the incidence of pain in facial areas including ears, nose, throat, and head. Further, pain was indirectly associated with respiratory problems including influenza. Allergies were the only symptoms mentioned by FMS patients which had no association with pain or any other FMS symptoms.

"Pain" was a universal characterised of every participant's FMS experience. The presence of pain was continuous (chronic) throughout the paradigm model. Besides being a FMS symptom (phenomenon), pain served as a pre-existing condition as well as a consequence of the causal conditions, intervening conditions, and as a motive for the application of various coping strategies in different situational contexts. The selective code of 'living with chronic pain' mediated the entire process of the paradigm model. 'Living with chronic pain' was the only selective code pervasive throughout all other selective codes. Further, 'living with chronic pain' was the only selective code that influenced the evolution and utility of all coping strategies. There emerged a recurrent relationship between living with chronic pain, participants' perceptions of pain, and participants' self-perceptions and behaviour.

Consequently, the selective code of living with chronic pain emerged as the core category of living with chronic pain. This emergent core category was supported by five crucial and indicative aspects of the FMS experience. Firstly, there is a change in pain perception for the same degree of pain severity reported by the majority of the participants as a result of having lived with chronic pain. Several participants reported an increased tolerance for pain. Typically, the same intensity of pain distressed participants less over time through a process of pain desensitisation. This increased tolerance for pain resulted from participants' interactions with continuous pain, their experience with successful coping strategies, and participants' acceptance of the condition and the pain.

*"got to become more tolerant because it's not something is ever gonna go!" (P6)*

*"The pain threshold's gone RIGHT DOWN, but the tolerance of it has gone UP." (P7)*

Secondly, the continual experience of living with chronic pain and the coping strategies that arise (or are prescribed) informed participants choice and use or disuse of subsequent coping strategies. Living with chronic pain informs subsequent use of coping strategies as a consequence of successful and unsuccessful applications of coping strategies.

For instance, when it came to patients behavioural adjustments and self-management strategies (i.e. behavioural coping strategies) (see Chapter Nine), most participants described a process whereby they 'learnt' coping strategies from their experiences of living with pain.

Thirdly, there are continual lifestyle adjustments, which the participants make on a daily basis in order to live with chronic pain in a manner that parallels normality (or a state they perceive as similar to normal) of healthy individuals. Lifestyle adjustment was an aspect specifically addressed within the interview. Participants described lifestyle adjustments made as they became accustomed to living with pain. Moreover, participants described their need to continue daily activities and participate in events in a way that 'appeared' normal, making adjustments that allowed them to continue living a normal life. Participants described how, as time passed, lifestyle adjustments become a routine and integral part of their daily self-management plan for coping with FMS and pain. Most participants described incorporating pain monitoring into their lifestyle so they could act to control the pain at an appropriate moment. This process directly underpins the adjustments they made to the application and cessation of coping strategies (discussed in Chapter Nine).

Fourthly, the degree to which FMS patients both seek and believe in medical interventions is prompted by the severity of their pain, and the success or failure of previous medical treatments and professional advice. Appraisals and decisions to seek medical intervention are often based on the severity of pain. During more severe pain episodes, other situational contexts such as level of interest in current activity, knowledge of pathological process, and length of time since onset (i.e., learning from previous pain experiences) affected decisions to seek and use medical intervention (i.e. drugs).

Fifthly, the level of social interaction and seeking of social support is directly associated with the severity and continuity of the pain condition. A pattern emerged whereby some participants either withdrew from social interaction when pain severity increased (negative linear association) or, in other cases, sought additional social support during more severe pain episodes (positive linear association). Thus, participants relied on social support as a coping mechanism in different ways.

Finally, the recurrent and pervasive nature of pain throughout all other categories acts as the final catalyst to its emergence as the core category in this investigation of FMS experience. Hence, living with chronic pain becomes the core category, which comprehensively conveys a continual and universally shared experience of FMS.

A core category can be considered a Basic Social Process (BSP) when it is the most central or problematic theme to participants in the investigated topic (Glaser, 1978). The BSP must be able to justify changes in interaction of a phenomenon, behaviour or problem inherent in various groups over time. More specifically, the core category becomes a BSP if it can explain changes, which occur chronologically. The core category must remain stable even when conditions vary considerably. Finally, the BSP discovered in the data must provide a summative statement that brings convergence to a large part of the variation in behaviour (Fagerhaugh, 1986).

In short, it would be reasonable to say that not only did living with chronic pain represent a core category as supported by the previously discussed five aspects of FMS experience, but also represents the basic social process (BSP). Firstly, the process of living with chronic pain was pervasive throughout all aspects of participants' lives since their FMS diagnoses. Secondly, behaviour, lifestyle, social interactions, medical interventions, and coping strategies changed chronologically in response to variation in pain type, site, and severity. Thirdly, while all other aspects of the FMS experience 'changed' the BSP of living with chronic pain, they only varied in proportion to the type and intensity of pain. Specifically, pain and how to live with pain on a daily basis appeared to be the only constant concerns for participants to live their lives and impacted on by every other aspect of the patients' lives. Finally, the repeated presence of living with chronic pain throughout participants' discourse despite the variation in topic matter led to its emergence as a central explanation of the FMS experience. The following chapters will illustrate in more depth how the participants' interview response support living with chronic pain as the BSP of the FMS experience.

## **CHRONIC PAIN AND CONTEXT OF LIVING WITH FMS**

The evolution, adoption and abandonment of coping strategies, expression of pain, behaviour, sociability, mood, and activity levels were influenced by the interaction of:

1. Severity of pain,
2. Length of time since onset of painful condition,
3. The current situation (that is, social and physical surroundings).
4. The level of success or failure of coping strategies.

Each participant described a variety of coping strategies, which they currently preferred and which were either applied in combination or singly, dependent on the context.

For example, at the time of interview, P6 preferred to use a combination of behavioural adjustment strategies such as stopping and resting, although she described applying other strategies as well. Participants' current preferences changed over time as part of the process of adapting to living with chronic pain.

Length of time since onset was associated with an attempt to minimise pain symptoms. Typically, long-term sufferers' preferred to ignore low-grade pain for a lot of the time without feeling the need to do anything about it. This was in contrast to nearer the time of onset and non-long-term sufferers, when they preferred to intervene at the slightest hint of pain. Participants who had experienced pain over long periods therefore described pain they experienced almost everyday with acceptance:

*"I just try to accept the fact that I DID have FMS."* (P2)

*"I just have to put up with it and it doesn't bother me. I just got used to it."* (P6)

Some participants described the use of Intentional denial or ignoring coping strategies. Through these techniques, patients appear to be attempting to change their interpretation of the experience and the severity of pain they experience through attention diversion:

*"I tell myself that it doesn't hurt."* (P5)

*"I say 'it's all in my mind' and try to keep going. ... go to bed at night and try to tell myself pain is not THERE."* (P8)

The corollary of minimising daily pain was that those participants who had experienced continuing and/or intermittent pain offered a qualitatively different attitude towards their pain and condition. That is, pain management was incorporated into participants' broader lifestyle with the intention being to live their lives as near to 'normal' as possible by minimising the difference between their quality of their lives (QOL) compared to their perceptions of a normal life.

Participants described how the severity of pain had an impact on their choice of coping strategies. As sufferers' experiences of using coping strategies increased, the coping strategies gained in refinement and became more effective in reducing the severity of pain. For instance, P1 described using self-distracting by continuing with current activity when experiencing pain, but as pain severity increased, she adjusted her behaviour strategy and began resting to cope. Thus, it emerged that any one coping strategy successfully covered an 'area' or 'range' of pain severity, and guided the sufferer about which coping strategy to use. In other words, the application and cessation of any one or combination of coping

strategies for any sufferer was dependent and moderated by the severity of pain at any one time. For example,

*“When I get severe pain in my leg, I prop them up on a gradual pillow structure, so there is no pressure on my knee. I lie there like that and I put my arms up on high pillows and my head back. So my body was on soft pillows. Same as my back. ... I prop myself in the right positions where I’m sore so the stress doesn’t continue.” (P1)*

It became apparent that since the time of onset patients individually developed a repertoire of coping-strategies, whose sophistication was relative to the time since onset and the amount of experience with FMS. As their experience grew, patients would learn through a process of trial and error which coping strategy to use for which level of pain severity, for which type of pain, dependent on situational context.

Situational contexts, which influence participants’ FMS condition and response, were related to:

1. Feelings of ‘being’ different.
2. Feelings of not wanting to bother people.
3. The degree of interest in a current activity.

The need to appear normal or not ‘being different’ was particularly salient in the social context, especially for the two youngest participants (P3, P5) in the investigation, and more so during the late formative years of adolescence. Although not specified, it was inferred that the need to belong to one’s peer group in a normal functional capacity may have superseded the need for relief and comfort from chronic pain. For instance, the decision about the need to intervene (and/or express pain) was balanced between severity of pain and current social context. P3 described her preference to carry cushions (behavioural adjustment coping mechanism) when attending movies and how this behaviour was blocked when in the company of her peers in public places despite severe pain from sitting for prolonged period:

*“I try not to be as different, that different. My mum tells me I should though, but, I’ve got stuff with them, it looks WEIRD. In public places.” (P3)*

The need to be emotionally independent and self reliant from significant others’ assistance and support when it came to the daily coping with the FMS condition was evident for P8 and P1. For instance, P8 intentionally shielded the symptoms of her FMS condition from her spouse and children in an attempt to protect them and improve her own coping. In effect, P8 utilised a combination of cognitive-behavioural coping

strategies of Intentional denial and attention distraction. What emerged was a complex combination of interrelated and interdependent cognitive-behavioural coping strategies, which helped to improved daily coping for P8. In the first instance, P8 exhibited the use of a Intentional denial strategy by ‘keeping the pain to herself’. She was protecting herself from her condition by protecting her family from its effects on her health. In the latter, P8 used attentional distraction in the form of counter-Intentional denial (or reduced acknowledgement) of her condition from her family, which helped her to ignore the pain. This coping strategy was additionally supported by her continual involvement in normal family activities. Finally, a sense of parental duty compelled P8 to suppress the provision of social support in order to ensure a ‘fair’ distribution among the family members.

*“He’s [husband] lost his job at the moment from Telecom. I could see that he might be going through a depressed stage too. So that’s why I’ve been keeping my own pain to myself. As long as I keep busy and don’t complain too much and don’t disrupt my kids too much with it and try and do the best I can. That’s how I cope. I’ve been trying to keep my problems to myself, my pain to myself, so I do and say as much to my kids as I possibly can without getting angry at things they do wrong.” (P8)*

On the other hand, P1 had utilised a similar coping strategy with her close friends. However, as P1’s coping strategies evolved and shifted she abandoned this particular mechanism because it resulted in a total withdrawal of social support when she really needed it (refer Chapter Eight, The Coping Strategies).

Finally, by identifying activities that promoted interest, many participants (P1, P2, P5, P7, P8) discovered a context that could be used as a coping mechanism. For instance, participants were aware that activities could distract/divert their attention from the pain, with several mentioning that they felt less pain and/or the absence of pain while engaging in these activities. This particular coping strategy, referred to as cognitive-behavioural distraction, will be discussed in Chapter Nine.

*“Like a really interesting TV programme, a really good book, then the distraction is good enough that you forget about pain for half of an hour, an hour, five minutes.” (P7)*

*“If I stop, I start thinking of the pain, but if I keep busy and concentrate on something, I get through. Perhaps the pain is there the whole time, but I’m thinking elsewhere.” (P8)*

Participants’ diagnoses, time since onset, and their understanding of the implications of their condition, as well as the interaction between their condition and their situation (including both the social and physical environment) operated as the situational context

which influenced their use of coping strategies. For example, P6 described how, with increasing experience of FMS, she had become more aware of the various implications of her situational context. She now utilised prevention strategies and refrained from activities that aggravated her pain and other FMS symptoms. Participants also described how not knowing the diagnosis, what was happening, and possible outcomes had served as intervening conditions for their condition and pain (discussed in Chapter Eight).

## SUMMARY

This chapter has presented the conceptual analysis that draws together the data from the participant interviews. The BSP of living with chronic pain links the data and accounts for a large part of the variation in behaviours described by the participants. Participants described an increasing tolerance for pain as well as daily lifestyle adjustments as they become more accustomed to and adapted to living with chronic pain.

The contexts, which influence the changing process of living with chronic pain and its constituent coping strategies and their interaction with medical intervention, were examined. A more detailed examination was made of chronic pain and the context of living with FMS. The first section explored the severity of pain, length of time since onset of painful condition, the current situation, and the level of success or failure of applied coping strategies. Finally, situational contexts, which influence participants' FMS conditions, responses, and the interplay with social support behaviour, activities, and characteristics of existence, were discussed in relation to feelings of 'being' different, feelings of not wanting to bother people, and the degree of interest in a current activity.

The following chapters describe the selective codes that constitute the process of living with chronic pain and the relationships between the codes and the participants' data on which the selective codes are based.

## CHAPTER FIVE

# The Causal Conditions of FMS

Throughout this report, the grounded theory paradigm model has been used to organise categories derived from the data. The first categories and relationships discussed are those related to the causes of *the phenomena*. Therefore, in this section, the participants' experiences of the causes of their pain will be discussed. The categories derived from the data will also be related to existing literature on the aetiology of FMS.

The aetiology of FMS syndrome (FMS) remains elusive, but it has been suggested that it is multifactorial with the inclusion of psychophysiological factors (Sarnoch et al., 1997). Though no one cause can be independently identified, suggestions of potentially salient variables have been made (Reilly, 1993). The data provided by participants in this study supports the proposal of multifactorial aetiology. Causal categories were identified as 'work-related accidents', 'non work-related accidents', 'specific psychological trauma', and 'dysfunctional background'. These categories were subsequently organised into two groups, specific and non-specific, each of which is discussed below. In addition, comparisons are made between reactive and idiopathic causes. Participants' theories of hereditary causality are also discussed. Finally, the issue of susceptible populations is considered.

### Specific Onset

Within the general category of 'specific onset', participants reported various causal conditions including occupation-related injuries, accidents and trauma. From the pool of eight FMS participants, three attributed the onset of FMS to work-related onsets alone (P3, P7, P8), two attributed onset to non-work-related injuries (P4, P5), and one attributed onset to a specific psychological trauma (P6).

*"I was working. I lifted it up, so upon all those newspaper[sic] and I strained it. ... I was a paper girl. ... Definitely ... I only developed THIS YEAR, but it was CAUSED by my back injury last year. ... there is NO DOUBT that if I hadn't had a back injury, I WOULD'VE NEVER EVER developed FMS."* (P3)

*"I had a car accident in 1978 and I had back problem since. ... When I had problems with my neck a couple years ago, the symptoms seem to be there. ... It's the accidents*

*and the chronic pain I've gone through in the last 3½ years that have triggered it."*  
(P4)

*"I was 10, I did a handstand and I landed on my head and my shoulder. They looked at my shoulder, but they didn't look at my neck. I have had problems ever since."* (P5)

*"The biggest thing was stress, shock. ... from the marriage. Then my father died and my mother in law was going too. That was shock to the system and set it going."* (P6)

Literature suggests that in 50% of the FMS cases onset follows an antecedent event, which is known as *reactive* FMS (Waylonis & Perkins, 1994, cited in Turk et al., 1996). Traumatic events such as emotional or psychological stress, injury or unusual physical activity, motor vehicle accident, surgery, influenza, or other viral-like infectious illnesses have all been reported preceding or concomitant with the onset of FMS (Greenfield, Fitzcharles, & Esdaile, 1992; Block, 1993; Waylonis, Ronan, & Gordon, 1994; Wallace, 1997). Other medical conditions, especially rheumatoid arthritis, may also trigger FMS.

Data from participants converges with these findings from the literature. These categories derived from the data support Waylonis & Perkins' (1994) aetiological classification and findings. That is, all participants have suffered from reactive FMS. Antecedent events were mainly traumatic, as proposed by Block (1993), Greenfield et al., (1992), Waylonis & Perkins (1994), and Wallace, (1997). Some of these events continued concomitantly with the onset of FMS.

### **Specific & Non-specific Onset**

In this investigation, participants presented various examples of non-specific onset. The most compelling was the testimony of P1. Her non-specific FMS progressed in an unanticipated manner, with her symptoms developing from a combination of factors. Various onset factors surfaced at different life stages throughout P1's childhood and adulthood. P1 identified a dysfunctional background as a potential contributor to her FMS condition. Her early experience included physical and emotional trauma, insufficient nutrition, lack of parental guidance and nurture, a squalid living environment, and a susceptibility to illness. She later identified psychological disturbances from a traumatic life as the primary cause of FMS.

*"I grew up in a very dysfunctional background. I wasn't taken to the doctors most of the time when I was sick because my mother couldn't afford it. I suffered a lot of pain. I've*

*actually had it ALL my life. ... I've experienced a lot of trauma as a child. Those things attributed to my health ... my father didn't provide so my mother was working two jobs to pay for things. We had poor nutrition and lived in squalid conditions. ... Health problems because we had poor nutrition. ... My mother smoked four packets a day when she carried me. She also had poor nutrition because I was the 7<sup>th</sup> child and she was at home and dad, still a gambler, wasn't providing well. There were a lot of attributing factors to my genetic makeup, having a weak frame. ... There was no understanding, a fear of doing anything, that I would be taken away, no encouragement, no recognition when you do do thing. No affection, no love in the family. Prior to 30, I was under constant barrage of attack. I TOTALLY believe NURTURING builds up those defenses. ... HOME was a nightmare for my health. Over the years, the trauma and the stress just beat me down."* (P1)

*"Stress (main cause). ... The things that battered them is TRAUMA. Trauma from rape, trauma from beatings. My father used to beat me severely, like a man! Trauma from severe sibling rivalry. Everybody would direct their aggressions to ME and my eldest brother, we were the scapegoats. There is VIOLENCE, SEXUAL and EMOTIONAL ABUSE. All these things ERODED my physical and emotional protections."* (P1)

P1 describes a reactive onset. She also describes characteristics more in common with *idiopathic* onset of Waylonis & Perkins' (1994) aetiological classification. According to Waylonis & Perkins' (1994), 50% of FMS sufferers have *idiopathic* FMS onset, where symptoms begin gradually and unexpectedly. These patients present a much longer history of somatic discomfort or physical illness that may originate at any life stage. Participants in this study reported experiences similar to those in other studies. Hurting "for years" or "my whole life" has been frequently reported (Boissevain & McCain, 1991; Block, 1993). Complaints about pain at onset are commonly treated as insufficient by medical practitioners to explain the disability that occurs (refer medical intervening condition in Chapter Seven).

P1's experiences of her family of origin seem to establish lifelong patterns. P1's upbringing entailed a disturbed and painful childhood experience, which affected her adult relationships. This led to a cycle of life long trauma, personality abnormality, and relationship impairment. Her suffering FMS is only one part of this:

*"Beginning with my family. I was molested between 4 and 10, and then I was raped at 12 by a brother, and then I was raped at 15 at a sister's house, and, relationships I've ever*

*had were all instigated through rape. I never knew how not to be situations were damaging for me because I was brought up in a damaging family. I went from one disaster to the other. ... I've never lived with a man. I stopped having relationships because they were ugly. I've been single for a majority of 13 years now."* (P1)

P1 regarded her upbringing as a crucial factor underlying the development of her personality. She described reciprocal associations between family, trauma, and personality, and saw her personality as a direct consequence of a traumatic family upbringing. For instance, P1 stated *"when you live in a state of constant trauma, you are not a responsible person"*.

Family also indirectly influenced individuals' personality traits through trauma. For example, obsessiveness was evident in the following discourse of P1:

*"Because of my sexual trauma as a child, I deal with feelings that come up from that by washing my hands. Suppose that's comfort. I can be obsessively clean. I am obsessive with use of space. ... I became OBSESSIVE when I was SEVEN. ... life that I was living was an absolute nightmare. Everything around me made me sick."* (P1)

Another effect of P1's traumatic upbringing is a tendency to overwork:

*"I do too many things. I just didn't have balance. There is no stop button. ... trying to block the pain of being molested, being beaten."* (P1)

Further, P1's account indicated that internalising negative feelings and subsequent anxiety were a consequence of traumatic upbringing:

*"It's c-o-n-s-t-a-n-t anxiety for me and my body is taking the brunt of it because there is no where else to put it. I've got this ability to leave it there. The ONLY one to share it with me is my daughter, so I internalise the blows. I don't talk about it [daughter's death] with anyone. ... take the blows and move on."* (P1)

For P7, a traumatic upbringing affected his preference for being alone (trait of loneliness), perhaps limiting his access to social support:

*"I come from a very bad upbringing, ... It's ['stay by myself'] an escape from being hurt. I've developed that as a child from the abuse I've suffered."* (P7)

Waylonis & Perkins (1994) found that idiopathic FMS was exhibited in conjunction with reactive FMS in one exceptional case. P1's experience is consistent with this finding. P1's FMS appears both idiopathic and reactive and she presented a long history of somatic discomfort (particularly pain) and various illnesses, which originated at various stages during her life. P1's case is also supportive of Jamison &

Virts' (1990) research which found that family support system can act as a causal factor. Specifically, this participant believed her traumatic upbringing, sordid living environment, physical and emotional abuse, family entanglement, rigidity, and familial addiction such as smoking both contributed to and aggravated the development of her FMS condition. In addition, her pain complaints were insufficiently recognised and treated by her medical practitioner.

Subjects in the present study did not follow the pattern of aetiology as suggested by the literature divisions of reactive and idiopathic onset. Presently, it appears these divisions and their proportion of causal explanation into 50/50 is arbitrary. In this study, participants could be categorised as 12.5% idiopathic and 87.5% reactive. The literature further suggested that FMS patients were either idiopathic or reactive. However, the present evidence suggests that participants had combination of reactive and idiopathic as well as multifactorial onsets.

Preliminary literature focusing on the contribution of family factors in chronic pain is rooted in psychoanalytic and family system approaches (Jamison & Virts, 1990). It has been proposed that chronic pain patients generally exhibit histories of an unhappy childhood, physical and/or emotional abuse, family entanglement, rigidity, and familial addictions such as alcoholism. Further, pain patients' families exhibit common occurrences of pain symptomology, levels of stress, psychological disorder, and alcoholism. According to these reports, then, chronic pain may be perceived as either developing from conflictual familial relationships or that these factors constitute vulnerability. Pain patients from non-supportive families reported a higher frequency of experiencing interference from pain, a tendency to not return to the workforce, and continuation of seeking other medical treatments (Jamison & Virts, 1990).

In conclusion, it appears that the assigned categories of specific and non-specific onset coincide relatively well with reactive and idiopathic aetiology classified by Waylonis & Perkins (1994). Specific onsets, including that of P2, P3, P4, P5, P6, P7, and P8, resulted from identifiable causal events, which reflect reactive onsets. Alternatively, P1 presented with a combination of a specific and non-specific FMS onset, where the non-specific onset developed gradually with no apparent causal mechanism as in the case of idiopathic onsets.

### **Comparative Effects of Idiopathic & Reactive Onsets**

The idiopathic and reactive FMS participant (P1) reported less pessimistic illness worries than other reactive FMS participants (possibly) because of her longer period of subjective habituation to illness and pain, and her extreme case of Type A personality (CR previous section and Chapter Nine for The FMS Employees: Type A Personality). Instead, she focused positively on necessary life modifications in order to pursue a near normal life (refer Chapter Eight, The Coping Strategies). Her experience supports Robbins et al.'s (1990) rationale that patients' illness worry can exacerbate FMS symptoms.

The comparison between reactive only and reactive and idiopathic participants in this study is consistent with Greenfield et al.'s (1992) comparative study, which found that patients with reactive FMS were more socially, economically, and functionally impaired for a prolonged period, and were at greater risk of losing employment. In terms of the severity, patients with reactive FMS had a more disabling pain syndrome. Turk et al. (1996) further confirmed that FMS sufferers with reactive onset have higher levels of pain severity, affective distress, a lower level of general activity, and more interference in functioning in comparison with FMS sufferers with idiopathic onset. In terms of the clinical severity, post-traumatic chronic pain like reactions in FMS patients (reactive FMS) could generate continuous and negative psychological and/or physical impacts (Waylonis & Perkins, 1994; Geisser, Roth, Bachman, & Eckert, 1996; Turk et al., 1996).

Results of the present study paralleled with Turk et al.'s (1996) findings that reactive FMS sufferers exhibited a higher level of affective distress and more interference with lowered level of general functioning than idiopathic FMS sufferers. Pessimistic feelings and lowered self-esteem was associated with limited daily activity and reduced prospects for future employment. This is supported by Gaston-Johansson et al. (1990). However, no confirmation on the level of pain severity could be made between the two categories of onset since all participants reported variations and episodes of the pain severity with subjective biases and no standardised statistical measurements were applied (Please refer to following chapters for supporting evidence).

## Theories of Hereditary Causality

As well as suggesting particular causes of onset, two participants (P3, P6) in this study also speculated that heredity was a possible cause, since, in both cases, some of their immediate family members suffered similar musculoskeletal conditions. P3 considered heredity to have been a partial cause since her monozygotic twin had a similar musculoskeletal condition: Occupational Overuse Syndrome (OOS). P6 and her brother were both diagnosed with FMS. P6 and her mother believed P6's father to have suffered from FMS since they shared similar coincident symptoms.

*"More than coincidence. There could be some hereditary thing cos my sister having OOS. They are quite similar in some regards."* (P3)

*"We don't know whether my father had it. My brother's got it. ... There must be some weakness in the family. I don't know what it is, my grandmother, they reckon she had arthritis too, my father's mother."* (P6)

*"We were wondering whether it's hereditary. I am sure my husband had it. They said he had arthritis, but he had same symptoms as what she's got. [her husband was] Very depressed. He had angina, probably all through stress."* (P6's mother)

The two participants who proposed a hereditary theory of causation believed heredity made them susceptible to FMS. In one case of reactive FMS, both the participant and her sibling's FMS conditions were triggered by marital trauma. She speculated, without medical support, that their father had suffered from the same syndrome without the sufficient medical attention to have the illness diagnosed.

*"Yeah, she's [P6] uptight, and Richard [P6's brother]. Your dad was. Very nervous, very sort of uptight all the time, can't relax."* (P6's mother)

This exceptional case coincides with Friedman et al.' (1987) proposition that Type A may be part of a *generic* illness-prone personality that predisposes individuals to a health problem such as FMS.

A familial, inherited pattern is common in FMS, although a precise genetic mechanism has not been isolated (Block, 1993; Ediger, 1991; Henriksson & Bengtsson, 1990; Henriksson, 1994). FMS can run in families, which suggests that some individuals may be more susceptible to developing the illnesses. However, future studies should be directed at validating whether the condition is hereditary.

## DISCUSSION

Participants in the present investigation identified the onset of their FMS condition in relation to some specific causal events. The vast amount of research on FMS indicates that it is a multi-factorial syndrome of chronic musculoskeletal pains and stiffness with unknown aetiology. However, a number of causal theories of FMS have been speculated, including the onset being provoked by genetic factors, accidents, previous surgery, a strained muscle, or grievous stress such as a death in the family, a financial burden, or family turmoil. Genetic/hereditary predispositions, non-restorative and abnormal sleep pattern, neurotransmitter deficiencies, and psychological disturbance have been implicated. Participants in this study introduced many of the factors. For instance, a theoretical link between the Type A personality and a genetic predisposition for FMS emerged from the data. Although preliminary, this link appears to reinforce Friedman et al's (1987, cited in Weiten, 1992) proposition that Type A personality are *generic* FMS prone groups. Despite this, two main categories of aetiology have been identified: reactive and idiopathic FMS. All participants from this study shared commonality of reactive onset of FMS. The present study demonstrated the inadequacy of existing classifications into idiopathic and reactive onset. In specific, participants in this investigation demonstrated characteristics of both types of onsets instead of the clear-cut categories proposed by the literature.

Pain was evident throughout all categories involved in causal conditions identified by participants. Participants suggested that heredity, upbringing, and adult relationships, as well as trauma, directly or indirectly, contributed to each patient's personality type. Personality then served as a recipient as well as an aggravating factor in causal conditions. In some cases, injuries resulting from work-related or non-work-related activities, which, in association with Type A personality traits, lead to FMS. This will be clarified in Chapter Seven (The Intervening Conditions) and Chapter Nine (The Consequences).

The multi-factorial onset of FMS in the present population may underlie the frequent difficulties patients reported while pursuing medical diagnosis (which will be discussed in medical intervening conditions in Chapter Seven). Speculation would suggest that the individuality and obscurity of FMS aetiology makes it difficult for medical practitioners to identify patterns in symptom with the result that proper diagnosis eluded both patients and their doctors until later in their conditions.

The persistent controversies about pathogenesis and aetiology of FMS have led researchers, and in particular, health-care-seeking patients, to consistently refer to the links of FMS with psychological and emotional distress, sleep disturbance, and functional impairment (Boissevain & McCain, 1991). However, despite the ambiguous nature of FMS aetiology from the clinical perspective, all participants in this study were assertive of the causal factor(s) of their FMS conditions and evident associations were made by their experiences of the aetiology of their conditions.

Overall, due to the wide spectrum of potential onsets of FMS, it may be reasonable to assume that the genesis may differ among the sufferers. It should be noted that what evidence there is for the aetiology of FMS is unsubstantiated, lacking in explanation of implications, and inconsistent between different FMS populations.

### **The Multifactorial Nature of FMS Aetiology**

Two participants (P1, P2) attributed their FMS onsets to a multi-factorial causation. One participant (P2) believed she had a dual-factorial causation, work-related and non-work-related injuries, which both progressed to FMS in their respective order, which has been supported by the clinical studies. P2 considered the work-related injuries to be the dominant causal factor in the development of her FMS.

*"Clerical, office work. The repetitive type of work I've been doing. ... and the results of accidents. ... It started with the neck problem initially. I had an accident on the bicycle, where I fractured my wrist. After that I went skiing and fell over and hurt my neck. And one of those light shades, the covers, fell on my neck... I slipped over a doctor's ramp. ... the repetitive type of work I've been doing and the accidents would be next." (P2)*

Another participant (P1) talked about a combination of two clinical categories of aetiology for her FMS. Her discourse revealed a hierarchical preference for an idiopathic cause with, to a lesser extent, a reactive cause. Of the reactive causes, P1 identified work-related injuries and psychological disturbance to be most prominent.

*"Long distance travelling could have totally caused my pain. ... part of that was work-related. Absolutely!" (P1)*

*"The result of many hard years and wrong kinds of treatments, stress and trauma. ... I had TWO daughters and one was KILLED seven years ago. ... I went through losing my daughter and being persecuted by my family at the same time. There was a lot of EXTREME and INTENSE emotional stress. ... the ultimate source of trauma."(P1)*

### **Posttraumatic Stress Disorder (PTSD) & FMS**

In a comparative study Amir et al (1997) found that individuals with posttraumatic stress disorder (PTSD) and FMS reported more nonarticular tenderness, more pain, higher functional impairment, impaired QOL, and suffered more psychiatric symptoms (depression, phobia, anxiety, paranoia, interpersonal sensitivity, hostility, and psychosis) than their those with just PTSD. They further suggested a strong association between the two disorders, and that reports on diffuse pain, pain sensitivity, and chronic pain syndrome in PTSD could describe undiagnosed reactive FMS. In the present investigation, P1 had suffered from a traumatic upbringing because of childhood molestation and series of physically and emotionally abusive relationships during adult life. Although not diagnosed with PTSD, P1 exhibited a congruent pattern of symptoms to the treatment group of sufferers with both PTSD and FMS in Amir et al.'s study (1997).

## CHAPTER SIX

# The phenomena

This chapter explores the emergence of the axial code of FMS symptoms under the 'phenomenon' category of paradigm model. There are six general sections in relation to the phenomena: pain, energy reserve, central & peripheral nerve system, visceral system, psychological symptoms, and external influences. Although each section is explored individually considerable interrelation occurs amongst them.

## PAIN

Seven codes of pain symptom were derived from the data: chronic pain, pain descriptions, pain analogies, lowered pain threshold, pain tolerance & pain descriptors, pain sites & pain severity, and pain types & its associated symptoms. Each of these is discussed separately below and associations with existent literature are drawn.

### Chronic Pain

Pain was described by all participants. Subsequently, it formed the basis for a substantive code during the open-coding stage of data analysis. During the initial analysis, pain was sub-categorised into duration, patients' descriptions of pain, severity, and pain sites. Apart from P5, whose pain experience was reportedly mild: "*uncomfortable*" and infrequent: "*I don't experience it all the time. Probably on a weekly basis there is some discomfort in my shoulders and neck and back*", the severity and duration of pain for the remaining FMS patients was described as severe and continuous. Pain was typically the first symptom these FMS participants recognised. For instance:

*"For the past FIVE YEARS, I've been back and forth to doctors. Because of PAIN. ... Groin pain, that's where it started."* (P1)

*"Two or three days later I developed a headache. ... There is definitely the pain."* (P8)

Generalised physical pain was reported by the rest of the participants as the most commonly experienced FMS symptom.

*"The PAIN."* (P1)

*"Pain. It's just constantly there all the time."* (P4)

Two participants (P2, P3) described pain as the most severe symptom of FMS experience.

*"Probably the pain and the sleeping bit goes together." (P2)*

*"Initially would be back pain. GENERAL PAIN and FATIGUE is the basic ones." (P3)*

Because pain is the recognised primary symptom of FMS, the ACR specified the criteria *'that all patients with FMS have widespread pain and tender points'*. Pain in FMS is generally continuous and prolonged (Henriksson & Bengtsson, 1990).

Almost all of the participants' reports from this study support Bennett & Jacobson's suggestion (1994) that pain is part of sufferers' lives and the most disturbing and persistent symptoms of FMS. Specifically, pain was typically the first symptom FMS sufferers experienced. "Hurt all over" and the permanence characteristic of pain marked the central property of FMS, which is consistent with the preliminary findings (Ediger, 1991; Wallace, 1997; Wilke & Corbo, 1989; Yunus, 1988).

### **Pain Description**

It appeared that there was a positive linear association between the severity of pain reported by participants and their level of mobility. Typically, the more severe the description of pain the greater the inhibition of mobility and participation in physical activities, and participants frequently described pain severity and in terms of inhibition of their level of mobility and activity:

*"SEVERE, CRIPPLING leak pain, where I'd have to stay in bed for days." (P1)*

*"I was LAID UP, I couldn't do anything on my own without my wife's help." (P7)*

Participants differentiated degrees of pain severity with descriptive adjectives and described variability of their pain. The extreme severity of pain was frequently described as *"really, really sore"* (P5).

*"Continually aching in my back and other muscles. It changes, sometimes I can have STABBING pain on my back, knees and elbows, it's DIFFERENT all the time." (P3)*

*"A dull pain to me is a LOW level of pain that will go on. ... being knocked or bang, with FMS, pain becomes INTENSE pain, which becomes EXCRUCIATING pain, which stays and keeps intensifying THEN eases out. It can take up to five minutes with the INTENSE pain to disappear so you can start breathing again. It's SO, SO painful that it's UNBEARABLE." (P4)*

FMS pain has been reported in both affective and sensory terminology. Descriptions of FMS pain among patients administered the *'McGill Pain Questionnaire'*, included sensory and affective descriptors such as: *"radiating, gnawing, spreading,*

*shooting, cold, unbearable, torturing, annoying, cramping*" (Baumstark, Buckelew, Sher, Beck, Buescher, Hewett, & Crews, 1993). Data in the current research concurs with this as demonstrated by the comments of P4 while describing the sensation of FMS pain.

A new form of pain description was found in this study. P4 and P6 used analogies to describe their pain. For instance, the term "*bruising*" was used as a descriptor for pain:

*"Say that you've got a quite a deep bruise and it's towards the end of the time you can just feel that, you know it's there. It's like that but at a sharper level."* (P4)

*"Yesterday, I felt like if someone actually kicked me [in the knee], almost as if I been bruised and your skin feels very burnt. But that's eased off a bit today."* (P6)

It was apparent that participants have learned to modify their expression of pain in relation to their prior experiences of social rejection of their condition. That is, they minimise or tend to avoid full descriptions of the pain suffered in response to social contextual cues:

*"Generally I put up a brave, smiley face for people."* (P3)

*"She's the ONLY PERSON, I've actually stopped telling people now."* (P7)

### **Lowered Pain Threshold**

Sufferers reported lowered pain threshold, with heightened sensitivity to pain over tender points. Many patients described a lowered tolerance for pressure induced through heat and physical touch because of their tender points. This situation was described by three participants (P1, P4, P6), who coped by limiting physical and intimate contact (CR p. 102 for limitation of physical contact of behavioural coping strategies).

Moreover, participants discussed an increase in pain intensity after physical activity. It appeared from their comments that physical activity could increase the level of pain experienced. Both P6 and P7 described inappropriate or excessive physical exertion, which resulted in more pain.

*"The pain is ALWAYS there. It increases with hard labour, mow the lawns, put up a shelf in the garage, try to dig the garden, work on the car, walking."* (P7)

The literature indicated that FMS sufferers commonly have lowered pain thresholds (heightened sensitivity to pain) over tender points, especially in response to pressure, heat, and electrical currents (Lautenbacher, Rollman, & McCain, 1994; Simms, Goldenberg, Felson, & Mason, 1988). They also experience a high degree of spontaneous, pervasive pain when compared to the normal population. The present

sample reported an increase in pain intensity after physical activity, which has also been documented in the literature (Bennett & Jacobsen, 1994).

### **Pain Sites & Pain Severity**

All participants, with the exception of P5, described the locality of pain as generalised to their whole body. Within this generalised pain, P2, P4, P7, and P8 expressed how their pain tended to be localised to articulating surfaces/joints and associated skeletal muscular structures. For instance the neck, back, shoulders, wrists, and legs.

*"It seems to be all your bones, all at once some days. Other days, its just the neck and shoulders. Other days it's the neck, shoulders, and the knees or one knee." (P7)*

There was also a tendency with most participants to have experienced severe episodes of migraines and/or headaches. For instance,

*"I am sore all over. I've had headaches for 3½ years. It's there all the time. Sometimes it hits migraine level. ... Non-specific pain throughout the rest of my body." (P4)*

The literature indicated that headaches, migraine, and facial pain are common complaints for many FMS patients. They may be caused by referred pain from tender neck and shoulder areas, or they may be associated with pain in the muscles and soft tissues surrounding the temporomandibular joint (TMJ), where the jaw meets the ear. In the latter case, jaw or facial pain is usually present too (Pellegrino, 1990).

Two patients discussed the presence of chest pain as a FMS symptom. For example,

*"I never used to get the chest pains, ... It's more of a cyclic thing." (P4)*

Although FMS does not involve the heart, FMS patients sometimes experience a condition called "costochondralgia", which involves muscular pain at the spot (the Sternum or breastbone) where the ribs meet the chest bone (Pellegrino, 1990). Since costochondralgia mimics cardiac symptoms, FMS should be suspected in patients with atypical chest pain.

The pain reported was typically musculoskeletal, although there was no pattern as to the locality of pain and pain descriptions among the participants. However, all participants expressed frequent shifting and/or spreading of the sites of pain as well as increasing severity of pain.

*"Has definitely got worse. ... My back injury kept on getting worse and worse and start getting neck pain, chill pain, and it just GRADUALLY spread over the last EVEN SIX months. ... Pain, EVERYWHERE. It JUMPS AROUND." (P3)*

*"The pain in the operated knee was WORSE and was always throbbing and aching, it seemed to be right in the middle of the knee, at the heart of the bone, then my other knee started aching and my shoulders and then my neck."* (P7)

FMS research indicates that sufferers often claim they "hurt all over" (Ediger, 1991; Wallace, 1997; Wilke & Corbo, 1989; Yunus, 1988). Nevertheless, pain is often most severe in certain locations or tender points, with most FMS patients initially suffering from localised pain (Henriksson, 1994). Pain is then reported to become more diffuse (less localised to the joints), spreading through the musculoskeletal system over a larger area, or in several regions of the body, or from head to toe. The criteria for FMS require that sufferers describe pain bilaterally, that is, *"in areas on both the right and left side of the body and above and below the waist"* (Block, 1993, p.65). The following sections will summarise some of the more common types of FMS pain symptoms and symptoms in general.

### **Pain Types & its Associated Symptoms**

Participants explained how the presence of continuous pain became a central focus of their lives throughout their experience of FMS. When describing pain participants talked about the types of pain and its associated symptoms and anatomical structures. These pain types were incorporated into one of the subcategories of pain according to their association with specific anatomic structures, including the skeletal system, visceral system, striated muscles, respiratory system, soft tissue sensitivity, and central and peripheral nerve systems. For example:

*"Immune system really low, fatigued, get everything else. This nose problem is a chest infection, which I get weekly. Last night I got chilblain and now pains in kidney."* (P1)

*"I've just got over tummy bug and that's made my back real sore. Dry skin, high blood pressure, migraines. I DROP things quite easy. ... I get the odd one [rashes]. ... It's part of FMS!"* (P6)

In musculoskeletal pain was prevalent amongst the participants. For instance, P7 describes the agony of moving articular surfaces and a type of pain associated with her musculoskeletal structure.

*"Getting up in the morning and not being able to bend my knees."* (P7)

Among the types of pain, two participants reported an increased sensitivity in the smooth muscles of the respiratory system. Both P1 and P4 related how the sensitivity of their oesophagus inhibited their ability to ingest food and fluids.

*"I've got a hair in my throat. It won't go away (by drink water). It will just be a micro that floats in the air."* (P1)

*"Occasionally choke, might be having water, seem to be happening more. ... muscle suddenly go into spasm and create problem with food or drink and way I go."* (P4)

The pain symptom activated a vicious rippling cycle upon the various anatomical structures, which created a whole raft of associated symptoms.

*"Any organ comes down with something. Whether is because you are fatigued all the time from pain or difficulty getting to sleep from pain."* (P1)

FMS is the commonest cause of chronic diffuse musculoskeletal pain (Schneider, 1995). Within the domain of FMS, pain is a multi-dimensional issue, which concerns, and presumably affects, cognitive, behavioural, motivational, affective, and neurological phenomena (Rummans, 1994, cited in Masi, 1994).

For instance, pain was reported to have directly caused FMS patients to experience a decline in the effectiveness of their immune and circulatory systems: *"part of the thing with FMS is your immune system is really low"* (P1). Also affected was FMS patients' cognitive capacity as evident in reduced ability to think and concentrate (P1, P2, P3, P4, P8). Also experienced was a decline in short-term memory (P4). It is possible that the decline in concentration produced the apparent reduction in short-term memory. That is, perhaps participants' impaired ability to remember was a result of reduced concentration. For instance:

*"Concentration is definitely gone down because my mind would just focus on pain instead of what I am meant to be paying attention in class or something."* (P3)

*"tested me with a long sentence and I didn't have the concentration to repeat it."* (P8)

*"I've got to be prompted to remember things. ... at night is worst, ... I've always been a thinking person and now I can't rely on my brain to bring forth what I need."* (P4)

These findings concurred with the literature where FMS patients frequently report cognitive impairment (Bennet, 1989; Wallace, 1997). Frequent complaints, which vary on daily basis, include difficulty concentrating, "spaciness", difficulties in "laying down" short-term memory, being overwhelmed easily, confusion, mix-ups with productive communication (speaking/writing), clumsiness, loss of co-ordination, and impaired fine motor control (Ediger, 1991).

## ENERGY RESERVE

Two categories of energy reserve emerged from the data: non-restorative sleep and fatigue. Each of these is explored below.

### Non-restorative Sleep/ Sleep Disturbance/Sleep Disorders

A link appeared between reports of increases in pain severity and poor sleep. Besides P5, who has always been *"a light sleeper and wake up pretty easily"*, all participant reported a link between pain and sleep disturbance. Participants reported difficulties staying asleep and/or rising early because of severe and continuous pain.

*"I've trouble getting to sleep, sometimes I wake during the night, often I wake during the night, and sometimes I awake early."* (P4)

*"A lot of the time I wake up during the night because I am in pain and can't get back to sleep, so I lie there, toss and turn for the rest of the night until it's time to get up."* (P8)

From a patient's perspective, complaints of poor quality, unrefreshing sleep are almost universal (Henriksson, 1994). Like most FMS sufferers, participants in this study reported waking up in the morning as if they had never slept or having slept for 6-10 hours yet remained feeling unrefreshed upon waking or more exhausted than when they went to bed (Yunus & Masi, 1985). Haythornthwaite et al. (1991) reported that poor sleep can potentially trigger FMS symptoms or vice versa and that sleep disruption is typically associated with the severity of pain experienced by FMS patients.

Sleep disturbance is one of the two (with the other being disorder of muscle function) predominant biological accompaniments to pain within FMS symptomology (Geel, 1994). Most FMS sufferers have abnormal sleep patterns (Moldofsky, Scarisbrick, England, & Smythe, 1975). Sleep disturbance is characterised by an interruption during individuals' Stage IV, *non-rapid eye movement* sleep. Stage IV sleep is also termed restorative sleep because a variety of central nervous system (CNS) amines and hormones are preferentially synthesised and released into the body during this time, including serotonin, growth hormone, and prolactin (Wilke & Corbo, 1989).

An effect of sleep disturbance was reduced energy reserves, which, in turn, affected psychological (P7) and cognitive wellbeing (P1, P2, P3). Moreover, this aggravated the types of pain and other symptoms experienced: *"I'm always fighting something, because I'm always fatigued."* (P1).

*"When I get up after my four-hour sleep or whatever it is, ... my wife sounded asleep. Yeah, it's pretty depressing."* (P7)

*"My concentration does (get affected) at times probably because I am tired a lot, I don't get a good night sleep and then you have to cope with the pain and stuff." (P2)*

*"Last night I got chilblain and now I am getting pains in my kidney." (P1)*

*"My arms are so lethargic they actually look crippled. I am sore now because I didn't actually have a good sleep. It's not unusual. ... I've got a low grade fever." (P1)*

Participants related fatigue to symptoms in the visceral system (P1), respiratory system (P1, P4), and central and peripheral nerve systems (P1, P7), as well as pain in facial sites (P1) and ear, nose, and throat pains (P7).

Sleep disruption is also considered as one of the most disturbing aspects of pain experience (Haythornthwaite et al., 1991). This has been supported by the work of Moldofsky (1976, cited in Haythornthwaite et al., 1991) which proposed a theoretical relationship between sleep features and pain-related constructs including pain severity, depression, and anxiety. Moldofsky's model (1976) proposed that chronic pain sufferers, including FMS patients, enter a vicious cycle of non-restorative sleep, fatigue, anxiety, irritability, depression and the development of chronic pain. Alternatively, Borkovec's (1982) "cognitive hyperactivity" model of non-restorative sleep suggested that both the central nervous system and sleep can be aroused by disturbing thoughts. Overall, the literature revealed an association between sleep deprivation and the initiation of other FMS symptoms.

## **Fatigue**

Most of the patients referred to fatigue as one of the dominant symptoms of FMS, which in most cases was as severe to them as the chronic pain. For example, P3 expressed it best when she said,

*"Initially would be back pain. GENERAL PAIN and FATIGUE is the basic ones." (P3)*

One participant, P5 described fatigue as the most frequently experienced symptom:

*"Fatigue, because that's basically a weekly thing. I am always tired and have been for many years."*

This data clearly agrees with earlier work conducted by Henriksson et al. (1992) where FMS participants considered fatigue as more disturbing than pain. Numerous patients consider fatigue to be the leading factor that inhibits them from living a 'full life' (Bennett, 1989b). About 80-90% of FMS sufferers describes moderate or severe fatigue with an associated lack of energy, decreased exercise endurance, or the kind of

exhaustion felt with the flu or with lack of sleep. The remaining 10-20% refer to “peripheral fatigue” (Bennett, 1989b) – an unusual exhaustion of muscles during physical exertion.

The effects of sleep disturbance may have partly caused participants’ constant state of fatigue, which in turn inhibited their physical endurance. Three participants (P2, P3, and P8) reported having experienced more severe fatigue towards the end of the day and P5 towards the end of the week. P3, P5, and P8 attempted to overcome their fatigue through sleeping.

*“I was really tired. I was going to bed at 8 so I’d be okay to get up at 6.30 the next morning. ... Friday I DRAG myself to work, do what I have to do and go home.” (P5)*

*“Night time is when I end up collapsing because I usually try and keep busy. I just switch out automatically and go to bed.” (P8)*

The effects of fatigue were a decreased quality of life, which will be discussed in Chapter Nine.

Further, P1, P3, and P7 established relationships between pain and energy reserves:

*“Fatigued all the time from pain.” (P1)*

Current data supports Wallace’s (1997) suggestion that fatigue may be due to a disturbance related to poor sleep habits and/or symptoms of generalised weakness in normal muscle strength, which prevents patients from getting restorative sleep. Individuals’ fatigue varies in terms of severity, timing distress, and levels of interference with daily activities. Psychological variables, such as depression and anxiety, can also influence patients’ fatigue severity (Gaston-Johansson et al., 1990).

## **CENTRAL & PERIPHERAL NERVE SYSTEM**

There is one main symptom of FMS affecting the central and peripheral nerve system. This can be linked directly to the neural symptoms of numbness & tingling.

### **Numbness & Tingling**

Also known as “paresthesia”, symptoms usually involve a prickling or burning sensation, particularly in the extremities (FMAGW, 1995). People with FMS may experience numbness and tingling in their hands, arms, feet, legs, or sometimes in their face. These symptoms were experienced by the present participants, who mentioned pain sensations

with a constellation of different adjectives. For example: dullness (P4, P6), ache (P2, P3, and P8), pins and needles (P2, P6), numbness (P2, P6), tingling (P6, P7, P8), and continuance (P2, P4, P6) were commonly evidenced.

Further, both P4 and P6 displayed a well developed knowledge of distinctive FMS pain in contrast to pain resulting from other injuries (P4) or other illness such as rheumatoid arthritis (P6).

*"From the back injury, I have numbness and pins and needles and burning. ... a VERY specific area of pain and very specific pain. ... With FMS, the pain is non-specific, over-generalised. It's always there."* (P4)

*"I can distinguish what pain it is, from that or the arthritis."* (P6)

## VISCERAL SYSTEM

### Abdominal Discomfort, Irritable Bowl Syndrome (IBS) & Irritable Bladder

FMS-related symptoms include digestive disturbances, abdominal pain and bloating, constipation, and diarrhoea. As a whole, such symptoms are known as irritable bowel syndrome (IBS) (Ediger, 1991). For instance,

*"irritable bowl syndrome, bladder control, itch skin, eye sight not the best at times, VERY VERY tired. ... hernia, that's sort of being treated."* (P6)

*"The diarrhoea started off, got worse and worse and it just that's all it was, ALL THE TIME. ... Before I had to wear panty shields, I had to stay at home. Pretty restrictive."* (P7)

FMS patients may also notice an increase in the frequency of urination and an increase urgency to urinate (Ediger, 1991). Often, no accompanying bladder infection is present.

## MUSCULATORY SYSTEM

There are two symptoms of FMS affecting the musculatory system, which includes muscle pain & weakness and stiffness & inflexibility .

### Muscle Pain & Weakness

Inactivity or disuse of muscles induces muscular pain, which leads to a reduction in muscle strength and endurance, and muscular atrophy. Due to the motor impairment

caused by dysfunctional central activation in the motor units (Backman et al., 1988, cited in Henriksson et al., 1992), FMS sufferers have a heightened perception that behaviour involving muscular exertion results in soreness and fatigue (refer **physical effects** in Chapter Nine). Exercise intolerance, poor physical tolerance, complaints of weakness, and functional inability all indicate defective muscle function and inactivity in FMS patients. Insufficient motivation, CNS fatigue, or relevant psychological aspects (such as perception of muscular effort and depression) can further limit sufferers' motor functioning that could contribute to weakened muscle strength.

### **Stiffness and Inflexibility**

*"I get up at night, I just fiddling around, the longer you sit the stiffer you become. I the morning I feel like a bus's run over me. ... this winter is the first BAD winter I've had about three years as far as being sore. I think it's SO damp." (P6)*

Stiffness in either muscles or joints arise typically as results of inactivity, which gradually becomes more conspicuous over time (Bennett, 1989b). Body stiffness at multiple locations is a significant problem experienced by most FMS patients (Ediger, 1991; Wallace, 1997; Wilke & Corbo, 1989; Yunus, 1988). This stiffness can occur upon awakening or as a result of remaining stationary for prolonged periods and may accompany weather changes.

## **PSYCHOLOGICAL SYMPTOMS**

In addition to the physical symptoms of FMS, there are a number of well-defined psychological symptoms including central psychological distress, anxiety & depression, and mood swings that affect FMS sufferers. Each of these psychological symptoms is explored individually and associations with relevant literature are linked.

### **Central Psychological Distress**

P1 and P5 reported no psychological disturbances from their FMS conditions, but all other patients reported some problems. P1 believed she was not emotionally affected: *"No, not at all"*. P5 rationalised with her insufficient knowledge of the FMS condition: *"I actually don't know much about FMS"* and her ignorance coping strategy: *"I ignore it"*.

For the rest of the participants, direct, sometimes reciprocal, effects and inverse relationships between pain, psychological wellbeing, and energy reserves were reported:

*"Sometimes I feel down, particularly when I am in quite a bit of pain and I haven't slept, I am just quite drained. ... I don't have as much energy so you don't always feel as confident, you don't feel good about yourself"* (P2)

Numerous studies have provided evidence of psychological effects among patients with FMS (Boissevain & McCain, 1991; Clark, Campbell, Forehand, Tindall, & Bennett, 1985; Goldenberg, 1986; Hudson, Hudson, Pliner, Goldenberg, & Pope, 1985; Mersky, 1989). For instance, Uveges et al. (1990) studied the psychological symptoms of primary FMS and reported that these patients experienced more psychological distress than patients with rheumatoid arthritis.

Gaston-Johansson et al. (1990) further indicated that psychological disturbances associated with FMS may partially correspond to reactions to physical stress and discomfort, the consequences of coping with chronic pain, and attempts to overpower being labelled as a "malingerer" or "fake". Psychological stressors were also found to affect FMS patients' pain-modulating systems, increasing pain perception and severity of pain.

One participant (P7) occasionally cried from the "*devastating*" tinnitus. Tinnitus was the only FMS symptom P7 was unable to control or adapt to. This was primarily because P7 found other FMS symptoms were manageable through the provision of medication and strategic management, and because "*99.9% of people cope because you have to*" (P7).

*"There is NOTHING for the ringing in the ears ... I'll have a good cry and 'why me'? ... a man 50 years old sit down and cry because ... what's happening in my ears."* (P7)

P7's tinnitus and P8's constant severe pain led to suicidal thoughts in the most extreme cases.

*"It's made me a couple of times quite SUICIDAL."* (P7)

*"Sometimes I find the pile of sleeping tablets might be the only way out. So, it is HARD. ... Two years back, I overdosed on sleeping tablets."* (P8)

Indeed, psychological disturbances has been reported to result from various factors associated with FMS including physical pain and fatigue, sleep disturbances, the experience of lack of legitimate acceptance of the problem of FMS, inadequate social support (refer to Chapter Seven, The Intervening Conditions, for further discussion), and

fear of job and relationship losses. For instance, Henriksson & Bengtsson (1990) proposed that a chronic pain disorder such as FMS, which diminishes sufferers' work capacity can also affect their psychological functioning and social status (refer Chapter Nine for Impact on Social Relations & Occupations). In some cases, this can lead to psychosocial difficulties, which, in turn, contribute to the overall symptomatology. They suggest that psychosocial problems are more "concomitant with or the consequence of" FMS, rather than the actual cause. Further, in a study conducted using the Minnesota Multiphasic Personality Inventory (MMPI) questionnaire, data indicated that central characteristics of FMS – number of pain sites and tender points, fatigue, and poor sleep – were more correlated with FMS itself than the psychological status of the sufferers (Yunus, Ahles, Aldag, & Masi, 1991).

Theoretical explanations that suggest FMS is a consequence of psychological distress or stress are not without opposition. Boissevain & McCain (1991) suggested that psychological disturbance among FMS patients is objectively well founded but difficult to explain. Specifically, the relationship between psychological disorders and the specific group of chronic pain symptoms characterised by FMS diagnostic criteria is not well known. Until an apparent causal relationship is empirically validated, they believe that it would be more expedient to treat "*psychological malaise as an integral consequence of the FMS experience*" (p. 243) instead of a concomitant predisposing factor for FMS.

#### **Anxiety and Depression** (refer to pp. 98-99 for more data)

Participants described being depressed (P2, P3, P4, P6, P7, and P8) or crying (P3) in response to their experience of being excluded from activities due to their condition. These same participants also anticipated the future pessimistically (discussed in Chapter Nine). P4 relied on verbal abuse and anger as a vent when she felt depressed.

*"You can REALLY get quite depressed about it. It's HARD being in pain. ... Sometimes realising the concept of the future, the WHOLE life thing is quite hard to grasp. ... you can't get out of the situation no matter how hard you try. You are kind of stuck."* (P3)

*"I've had times of depression. ... It was an inwards looking anger. It was 'why me' and 'I am useless' and all these sorts of things."* (P4)

*"I'll have days when ANYTHING can SET ME OFF CRYING. I don't know WHAT IT IS, you pass the 'what am I crying about' phase until you cry for the sake of it."* (P3)

Depression and anxiety are prevalent and appear to be among the dominant group of FMS symptoms (Boissevain & McCain, 1991; Hawley & Wolfe, 1991). Comparative studies revealed a higher frequency of anxiety and depressive symptoms among FMS patients when compared with a control group of other rheumatologic patients with pain (Hudson et al., 1985; Goldenberg, 1986; Krag, Norregarrd, Larsen, & Danneskiold-Samsøe, 1994). About one-third of the patients with FMS from a rheumatology clinic population have significant psychological distress, such as anxiety and depression (Yunus, 1994). At the time of their initial diagnostic appointment a median of 18% of FMS patients suffered from major depression, compared with a median of 58% depression for long-term sufferers of FMS. This rate is higher than for any other rheumatological condition, but it appears that most FMS sufferers are not depressed most of the time (Wallace, 1997). Amir et al. (1997) indicated that there appears to be great variability among FMS patients and that some might be more vulnerable to other illness.

The relationship between negative affects – namely anxiety and depression and chronic pain syndromes – has always been a ‘chicken and egg’ problem. The depression and anxiety that seem to follow the onset of FMS symptoms may be the result of the FMS rather than a cause of it. Many patients with FMS are anxious and depressed, but this is usually secondary to the illness rather than being the primary concern (Wallace, 1997). Patients suffer depression because they hurt all over and feel tired all the time.

In the present FMS population depression was common, which related to the theme of loss – of self, of health, of control and independence, of employment, and of relationships (refer Chapters Eight and Nine for perceived emotional states and illness impact respectively). Again, depression appeared to be hard to separate from physical symptoms of FMS, as identified by Wallace (1997).

### **Mood Swings**

The major emotional effects of FMS symptoms and pain were mood oriented. For example, P6 used medication, while P8 relied on a withdrawal strategy to prevent severe and frequent mood swings.

*“I used to, until I am on Prozac, my mood swing was very bad.” (P6)*

*“sometimes things they (kids) do wouldn’t bother me, but then some days I get really worked up with something really that’s not a big deal.” (P8)*

Changes in mood and thinking are common in FMS as indicated from the data above. Mood swings may be accounted for by sleep deprivation and a loss of opportunity to regulate serotonin during Stage IV sleep. Serotonin is a neurotransmitter which regulates emotion and sleep patterns (Chaplin, 1985). People with chronic pain typically show evidence of lowered mood and preoccupation with somatic symptoms. Mood is significantly associated with pain intensity and both are typically at their worst in the morning with improvements during the afternoon (Vendrig & Lousberg, 1997). This morning trend may come about after waking from a night of unrefreshing sleep when serotonin is depleted.

## EXTERNAL INFLUENCES

### Environmental Sensitivity

Informal surveys reported that FMS patients have higher than average tendency to allergies or at least come from families where allergies are common (Ediger, 1991). Allergies were the only symptoms mentioned by FMS participants that had no association with pain or any other FMS symptoms.

*"I have itch skin ... dry skin ... I get the odd one [rashes]."* (P6)

Allergic-like reactions to a variety of substances are common, as are sensitivities to light, noise, odours, and weather patterns. Dryness of the skin, eyes, and mouth is also common (Ediger, 1991).

## DISCUSSION

Pain both originated as the first FMS symptom and acted as a catalyst that gave rise to an assortment of associated symptoms. For instance, sleep disturbance was commonly experienced by participants because of continuous pain that contributed to reduced energy, fatigue, and further pain.

Supportive of preliminary findings (Amir et al., 1997; Kurtz et al., 1998), the study indicates that FMS is a complex of both somatic and psychological symptoms. Specifically, parallel with Kurtz et al.'s (1998) reports, numerous FMS somatic symptoms were found to be interrelated in a cyclical manner with ripple effect originating from pain that weakened participants' condition. In some cases these cyclical

and ripple effects burdened participants with further psychological distress as mentioned in the Copenhagen Declaration (1992), Kurtze et al. (1998), Gaston-Johansson et al. (1990), Henriksson & Bengtsson (1990), and Wallace (1997). For instance, consistent with Wallace's (1997) proposition, participants considered their fatigue to originate from their disturbed sleep patterns and/or symptoms of generalised muscle weakness. This resulted in pain and soreness, which prevented sufferers from having restorative sleep. Backman et al. (1989, cited in Henriksson et al., 1992) also stated that activities engaging muscular exertion inflicted sufferers with soreness and fatigue. Parallel with Hanricksson et al.'s (1992) study some participants felt that fatigue sometimes dominated over pain as the most severe symptom. Specifically, the continual fatigue inhibited FMS patients' achievement of daily activities. In common with Bennett's (1989) suggestion, insufficient energy, decreased exercise endurance, and exhaustion derived from sleep disturbance were typical among participants who experienced moderate to severe fatigue.

As proposed by Affleck, Tennen, Urrows, & Higgins (1992) Stone et al. (1994), and Totterdell, Reynolds, Parkinson, & Briner (1994), participants reported that the severity of chronic pain, fatigue, and sleep disturbances were predictive of their daily emotional wellbeing. Psychological distress, typically depression and anxiety exacerbated participants' level of fatigue, which appeared to induce other FMS symptoms.

Participants recurrently emphasised depression as part of the dominant symptoms of FMS in accord with Boissevain & McCain (1991b) and Hawley & Wolfe (1991). To some participants, depression did, at some stages, become the primary concern even though Wallace's (1997) proposed that depression is secondary to the illness since depression results from general physical distress. Besides being partially correlated to reactions to physical discomfort, psychological distress was also the consequence of participants' coping strategies and attempts to overcome being labelled as a "malingerer" or "fake" as proposed by Gaston-Johansson et al. (1990).

In summary, FMS symptomology includes a range of physical and psychological problems with musculoskeletal pain, tenderness, and fatigue prominent. Increasingly, additional symptoms and syndromes are being associated with FMS. This became evident in the present investigation when new forms of symptoms emerged, which will be discussed in Chapter Nine, The Consequences.

CHAPTER SEVEN

The Intervening Conditions

This chapter investigates the axial codes and categories generated from current data and corresponding with ‘intervening conditions’ of the paradigm model. Whether individually or in concert, intervening conditions were coded under categories of Finance, Person-Orientation, Medical-Oriented, Information & Awareness, and Social Support. These intervening conditions were reported to either inhibit or enhance the pain experience. The intervening conditions of financial, social support, and information and awareness each had a direct effect on both medical and person-oriented intervening conditions, while the medical intervening conditions influenced the person-oriented intervening condition. The participants’ experiences with these intervening conditions are summarised in the following table and will be discussed separately in detail:

	P1	P2	P3	P4	P5	P6	P7	P8
Financial intervening conditions	-	+	-	-/+			-	-/+
Person-oriented intervening conditions	-	-	-	-	-	-	-	-
Medical intervening conditions	-	-/+	-/+	-/+	-	-/+	-/+	-/+
Information & awareness intervening Conditions		-	+	-	-/+			-/+
Social support intervening conditions	-		-/+	-		-/+	-	-/+

Key: + = Positive influence on FMS  
- = Negative influence on FMS

Table 1. The intervening conditions of FMS sufferers’ experience

Variables categorised in this study as intervening conditions resemble ‘aggravating factors’ from the literature. The literature documented various aggravating factors, but no in-depth arguments were made. Participants in this study, on the contrary, have provided much greater detail about individual intervening conditions. The existent literature relevant to intervening conditions is discussed last.

## FINANCIAL INTERVENING CONDITIONS

Financial intervening conditions are composed of institutional (usually governmental) subsidy assistance, which, when present, acted to maintain or improve patients' conditions. Specifically, three codes of financial intervening conditions were derived from the data: ACC, Work & Income New Zealand, and Medical Costs. Within the financial intervening conditions, ACC and Work & Income New Zealand mutually influenced and mediated patients' expenditure opportunities and the affordability of their medical costs. Reimbursement from ACC and medical subsidies provided by government departments such as Work & Income New Zealand allowed FMS patients to cover and/or reduce their medical costs for consultations, medications, treatments, and ergonomic assistance, as well as provided Home-Help assistance. For instance,

*"ACC is paying for home help, I am getting 12½ hours a week home help." (P4).*

*"claim for any medication and through ACC and my plan supports like they reimbursed me travel allowance. ... cover me when I had treatment with the chiropractor, acupuncture and osteopath, and physio, but still have to pay surcharge. ... on the Community Services card, I went to the psychiatrists ... free of charge." (P8)*

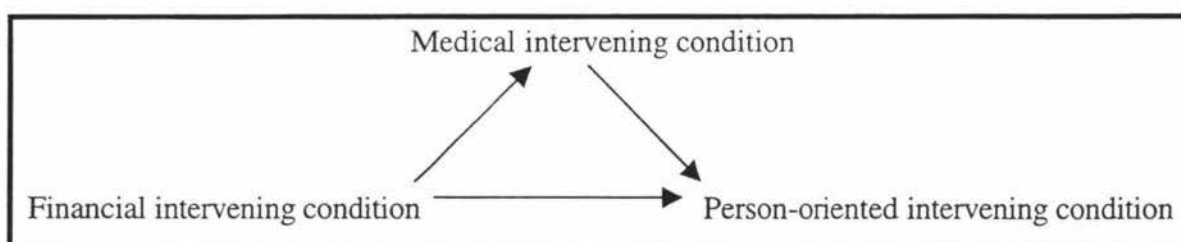
Regardless of the varied reactive onsets of FMS, perception of physical trauma was found to be a more significant determinant of disability compensation for FMS than perceived emotional trauma, severity of symptom, or functional disability (Greenfield et al., 1992; Aaron et al., 1997). Consistent with Greenfield et al. (1992) and Aaron et al.'s (1997) propositions, participants (P3, P4, P8) whose FMS was of reactive nature received disability compensation mainly due to their claims for physical injuries. However, ACC and Work & Income New Zealand requires the medically identifiable presence of physical trauma as part of its criterion for granting financial assistance. In addition, the nature of physical trauma must impair the individual from participating in employment.

However, FMS participants who received such financial aid referred to the amount of subsidy as insufficient and alluded to the need for additional sources of financial support to cover the medical costs. For example, P3 and P8 compensated for the deficit in their medical coverage through parental assistance and work, respectively.

*"only a very pathetic amount and not even covering the medical cost. My parents cover most of it." (P3)*

*"I am only getting a small amount, but it does help sometimes. So the little amount I was getting from disability allowance helped me cover because when your husband is on the dole, you haven't got a lot money come into the house. ... what I work for I am still hoping contribute to the household."* (P8)

The ACC financial intervening condition appeared to influence person-oriented intervening condition, as well as the medical intervening condition. Whether directly or indirectly through the medical intervening condition, the financial intervening condition seemed to improve or reduce individuals' physical and psychological wellbeing.



**Fig. 4. The association between person-oriented intervening condition, medical intervening condition, and financial intervening condition**

For an extended period, P3 experienced delay in responding to her request for ergonomic assistance from ACC and eventually relinquished this petition. P8 encountered complications of her condition when ACC did not recognise FMS as compensatory. The conflict was resolved once her GP proved her causal condition to be a work-related injury.

*"they haven't done anything about it and they've been putting off and off and off, months, so we've kind of given up on that idea of getting me better chairs."* (P3)

*"my own doctor has had proof and said it was definitely the accident. ... They've still been paying my claims. ACC has been reimbursing me back."* (P8)

P7 received ACC's assistance and eventually obtained a referral from his GP after ACC's request for an additional assessment of his condition.

*"My GP did not refer me to an orthopaedic surgeon, until ACC said to my GP in January 1997 'this is not good enough, we want a second opinion'."* (P7)

Participants who have not received (P1, P7) or have lost (P4) such financial aid encountered additional difficulties in their management of FMS. The severity of their physical condition was exacerbated by financial constraints. P1 and P7 suffered from ACC's non-recognition of their medical condition in that they could not afford the treatment and medication they believed would maintain or improve their physical state.

*"I got no help from ACC, quite a mental. ... He gave me eye drops and I hardly felt the pain at all! I can't afford that. Cost a fortune to go to doctors these days." (P7)*

P4's somatic condition deteriorated to the stage that she was physically unable to maintain employment. Specifically, she reported the withdrawal of her ACC subsidy for physiotherapy resulted in a relapse of her condition to a state where she could not return to the workforce.

*"can't afford to go. ACC pulled the funding for me to go to him. I never regained that, where I thought 'neat! I'll be able to work'! ... another point where I collapsed." (P4)*

One participant (P2) receives another form of financial aid that provides various kinds of occupational assistance. Their principal concern is to prevent and minimise work-related hazard or injury.

*"Because I am with Work Bridge, they pay for occupational therapist to come in and when I am in a job, they set up a work station. That's really helpful." (P2)*

It became clear that most participants considered external financial support necessary or beneficial to sustain or improve their FMS conditions.

## PERSON-ORIENTED INTERVENING CONDITIONS

The person-oriented intervening conditions include aspects of the FMS patient's social sphere, daily habits and practices, experiences, history, and characteristic behaviours. The person-oriented intervening condition was the only category influenced by all other intervening conditions since various forms of 'external mediators' impacted on individuals physical and psychological wellbeing. Associated manipulations, external influences, and personality & history were the three categories of person-oriented intervening conditions. The latter two immediately affected on the first, which resulted in pain.

Most participants in this study evidenced a similar personality trait known as Type A personalities. Individuals with Type A personality are typically ambitious, hard-driving perfectionists who are tenaciously motivated to overcome obstacles, driven to accomplish set goals, are extremely time conscious and impatient, as well as exhibiting competitive, aggressive, and hostile behaviours (Burger, 1993; Weiten, 1992). Type As tend to set higher goals and standards for themselves than do their polar opposite counterparts, the Type B personalities. Based on this definition of the Type A personality and the personal descriptions given by subjects there emerged an overlap in the characteristics described in

both, with three participants in this study descriptively consistent with type A personality. Those with a Type A personality were sub-categorised into individuals with excessive work application, with a drive for completion, with a personality imbalances, with trait loneliness, and with internalisation of negative feelings, as well as being over-achievers and perfectionists. All participants explicitly identified themselves as over-achievers. Although not explicitly stated by every participant during the interviews, three participants (P1, P6, P8) concluded that their personality characteristics served as another causal condition of FMS.

*"Personality, besides stress, could have some contribution to FMS. An uptight, methodical person, things got to be done right person. Can't relax. Even when I am having a rest, I sort of relax and think 'STAY like it', you can feel yourself tense."* (P6)

Along with her mother and her GP, P6 speculated that her personality characteristics could have instigated her FMS condition as well as her psychological disturbances.

*"you have to be an uptight person as well to end up with this problem. Very nervous, can't relax [mum]. ... YEAH! That's [perfectionist] what Dr. Wong said, 'your mind's got to be tidy, you've got to know where you're going, what you're doing', and I said 'yes'. He said that's the reason why I am more likely to get it."* (P6)

Another participant (P1) realised that her personality characteristics – introverted personality traits, including internalisation of general negative feelings and perceived vulnerability – precluded her from receiving desired and adequate social support from significant others. These personality traits were expressed through Intentional denial of her condition and rejection of others' assistance, which helped her to feel in control of her condition, and hence, reduced feelings of vulnerability and helplessness.

*"I'm fine! Nothing wrong with me!" ... when I needed understanding I wasn't getting it. I've taught them I don't get sick, don't need help. ... because I feel vulnerable."* (P1)

The external influences comprised three dimensions: Arousal Level, Activity Level, and Climatic Conditions. Arousal level was defined as the state of both physical (P5, P6, P7) and mental (P4, P6) alertness and activation. Four participants claimed that arousal level could affect other aspects of their physical and/or psychological condition. Both P6 and P7 described inappropriate or excessive physical exertion, which resulted in more pain.

*"The pain is ALWAYS there. It increases with hard labour, mow the lawns, put up a shelf in the garage, try to dig the garden, work on the car, walking."* (P7)

A loss of sense of control triggered by external factors was indicated by both P4 and P6 who reported an increased level of stress.

*“Situations where I am not in control. You put me in a stressful situation and I don’t cope well now. If I’ve got too much happening, I just have to shut down.” (P4)*

P4 identified ACC’s media announcement that they would withdraw financial aid from FMS patients as another intervening condition that contributed to her psychological distress.

*“Suddenly ACC are going to knock FMS patients on the head. It was HUGELY stressful. ... the THREAT of that.” (P4)*

Four participants suggested that prolonged isometric contractions and fixed position might have interfered with their resultant physical state without directly causing the development of FMS. For instance, long distance driving (P1, P2), working overtime (P2), invariant school timetables (P3), and changes in physical activity from a state of activity to rest (P4):

*“I went from a lot of exertion in my upper body to very little. ... My arms too begin with throbbing. ... It is the STEERING, the upper body in severe pain, but the legs are in there too. ... It’s manual. That’s (change gear) was tiring. ... constant barrage.” (P1)*

*“The first job, we had to do a lot of over time. I got that a lot.” (P2)*

*“Sitting for a-g-e-s at school. The school chairs cause SO MUCH pain for me.” (P3)*

*“a two-edge sword. If I stopped moving and lay down, I would be worse, it would come right for a while, but I would actually end up worse. That would set my spine off.” (P4)*

Similarly, P4 took extra care to prevent illness in order to avoid suffering more pain associated with bed rest, which aggravated an existing back injury.

*“I do everything I possibly can not to get sick. If I spend 24 hours in bed, that I am gonna have real problems with my back.” (P4)*

P4 also stated that over-sleeping and inactivity, resulting from taking sleeping tablets during episodes of absolute exhaustion, triggered further pain.

*“18-24 hours of sleep with one of those things. ... I’ll suffer the next day because I’ve been sleeping, because I’ve been lying down all that time. The pain starts.” (P4)*

Lastly, climatic conditions played a significant role in mediating the severity of these participants’ FMS conditions. Climatic condition refers to prevailing weather trends and seasonal changes. P8’s adverse reaction to hot and humid climatic conditions was contrary to other participants.

*"Hawkes Bay. The climate is very HUMID up there. I get very exhausted QUICKER than what I do down here. Heat does affect me, humid rain and hot will affect me".*

The remaining six participants stated that the dimension of climatic conditions including cold, dampness, and rain, combined to worsen their level of pain perception (P1, P2, P4, P5, P6, P7), and cognitive functioning (P1). Both P4 and P7 reported they had worn more clothing since the onset of FMS due to their increased somatic sensitivity to coldness. The increasing sensitivity towards climatic conditions underlined an increased vulnerability and fear to becoming ill.

*"Cold and dampness. ... Can't move. Can't operate. Can't think. Can't do nothing. ... The slightest bit of cold air and I am right awake and experiencing discomfort." (P1)*

*"I am more sensitive to cold. Cold, rainy day, I get very cold and I've got to be careful. I keep my back and chest warm. If I get cold I shiver, which makes it worse." (P4)*

## MEDICAL INTERVENING CONDITIONS

The medical intervening condition can be described as medical consultations, medically administered treatments, and/or medications aimed at modifying FMS patients' conditions in a favourable manner. This intervening condition is composed of medical interventions, which acted to elevate and/or induced suffering. Misdiagnosis, inefficacious treatment, insufficient knowledge, complications, and medical practitioners' attitudes (i.e., personal beliefs about and feelings towards the existence of FMS) were the five general codes of medical intervening conditions that participants believed could influence their conditions. Medical intervening conditions produced immediate physical and psychological consequences. Although there were both positive and negative remarks, most patients reported various difficulties and failures while seeking medical assistance. Medical practitioners' attitudes and beliefs towards FMS patients and their condition were reported as ignorance (P1, P7), inaction (P1, P4, P5), and negative attitudes (P1, P7). FMS patients also reported a lack of access to medical information and educational material from their medical practitioners (P1, P3, P7), which they believed aggravated their physical conditions.

*"Doctors hadn't taken me seriously in the very beginning. ... So I ended up with physical stress. There was something serious wrong. ... One doctor even told me I should get a PENIS because I haven't been sexually active for years. At the same time, my health*

*system is breaking down and still no diagnosis. ... they never ever heard me, which I told them at every single appointment it (groin pain) was no where near the period time. ... His (GP) services, his bedside manner has got worse or less caring. the SUBJECT ENDS when I LEAVE THE CLINIC. As soon as he's signed, I paid, it's over. He is not interested in finding a solution."* (P1)

*"I believe the inaction on the problem that I had, the fact that when it went from acute to chronic there was no action, caused the problem."* (P4)

*"A lot of doctors have bad attitudes about women because all of them have put it down to me being a neurotic woman and I was having PMT."* (P1)

*"I asked for some ideas and he didn't give me ANY ideas."* (P1)

Medical practitioners' ignorance (P1, P4, P8), insufficient medical knowledge (P3, P6, P8), a lack of adequate explanation and knowledge of patients' FMS by medical practitioners (P3, P5, P7), and negative feedback (P3, P8) worsened several participants' psychological distress. Medical practitioners' ignorance was evident when they did not validate participants' complaints of their physical health (P1, P8) or questioned participants' claims (P4, P8) providing increased emotional distress for the sufferers.

*"Nobody is listening! The doctors weren't hearing me.... I am feeling very depressed because I feel like he stopped taking me seriously."* (P1)

*"back from my notes of the psychiatrists, I said I wasn't depressed at the start. They've been trying to swing it around. It's hard, because I felt perhaps I AM WRONG."* (P8)

Participants believed that because of a deficit in the medical practitioners' knowledge of the FMS condition, their pain experiences were not diagnosed (P3) or acknowledged (P6, P8). As a consequence, the treatment was ineffective or inappropriate, which led to an increase in patients' psychological stress. P8 indicated her depression had worsened because her psychiatrists had failed to recognise pain as the root cause of her depression.

*"FRUSTRATING. They KNEW it wasn't normal, but DIDN'T know what it was."* (P3)

*"I got my depression worse in one way because I knew I was in pain, but the people I was talking to couldn't see that. They were saying depression was causing pain, not pain to depression. I was in pain and yet nobody was listening."* (P8)

The inadequate provision of educational material about FMS to FMS patients from health professionals (P3, P5) and the lack of referral to counselling (P7) led many sufferers to a state of indifference and loss of 'respect' for their GPs.

*"I don't find Dr. ... a GREAT help to me. He just diagnosed it. He's explained VERY BRIEFLY but it's a bit different from what he says and what I experienced later on. ... but, it has been quite bad, so a little bit of a shock really." (P3)*

*"would've helped if there is somewhere I could've gone to. I went to my GP and said 'I am pretty depressed, feeling pretty, pretty down, suicidal and he said 'yeah. You'll be all right' and patted me on the shoulder and off I went again and paid \$35 for it." (P7)*

Negative feedback from medical practitioners (P3) and other difficulties (P8) further contributed to participants' emotional distress.

*"Physio kept saying I've got a back like a 50 year old, which was upsetting." (P3)*

*"yeah [more angry or depressed]. A lot of them they said that I failed to turn up for their appointments. That finally got proven that their notes was incorrect." (P8)*

In this study any participants believed that their poor physical (P1, P2, P4, P8) and psychological (P8) states could, in part, be attributed to medical practitioners' lack of diagnoses (P1, P5, P6) or mis-diagnoses (P1, P8). Participants (P2, P3, P4, P6, P7, P8) generally experienced delays receiving diagnoses, referral, or treatment. For instance, P4 identified the delay in physiotherapy treatment as the core of the exacerbation of her medical problem.

*"The problem was, it wasn't diagnosed. ... I still haven't had a diagnosis. I am going in for throbbing legs, swollen knees, headaches, fatigue, I kept getting all those things wrong with me. ... My doctorS have all misdiagnosed the past five years and their names don't seem to be on the chopping blocks. But my HEALTH has." (P1)*

*"They said it's concussion and time will take its course and nothing changed. ... put me in Lake Alice for a section under 21 for depression because I can't live in pain anymore and right up to this year, I've been told it's all in my mind. I was getting a lot of colds and they said 'it's the depression', a really good excuse for a lot of them. ... if I was told FMS earlier I may not have gone through such state of depression." (P8)*

*"I got diagnosed over two months ago, but I've had symptoms over a year now." (P3)*

*"If I'd been given proper physio and all the other psychological stuff 3½ years ago, then this probably wouldn't have gone on the way it has." (P4)*

*"referred me to rehab but it's three-month waiting before I get to the other. ... always a lot of waiting I have to do. I am experiencing a lot of pain between all these, I bear it. ... taken eight years for somebody come out to say something other than depression." (P8)*

Three participants (P1, P4, P8) reported negative reactions to their prescribed medication. P1's doctor's negative perceptions of her personal appearance and presentation lead to a reluctance to prescribe medication. A second doctor appeared to prescribe medication inappropriately with the resultant degeneration of P1's condition.

*"The doctor in Feilding treated me as neurotic. He gave me three antibiotics, I was getting sicker and he put it down to other drugs. ... pain got so severe, the doctor in Palmerston North put me on contraceptive injection. I started period 17 months non-stop! Every time he just gives me more drugs. ... paying through my nose, but not getting any better. ... I have been mismanaged with my health."* (P1)

*"Prozac to help me with the pain and I couldn't eat, drink. It shut everything down and with sleeping tablets, I started menstruating and I just keep getting worse and worse. I did get into a cycle because of the allergic type reaction."* (P4)

P8 found it traumatising when new psychiatrists interpreted her behaviour and attitudes solely from her case notes. The outcome of this was that P8 could not develop an open and trusting relationship with her psychiatrists. Typically, she felt that her psychiatrists were heavily influenced by her case history. Because of her lack of trust and confidence in her psychiatrists, there was little or no progress in her treatment.

*"One psychiatrist put me down I was a nutter. It's more stress to try and work out why. ... this particular psychiatrist ... put in my notes I had behavioural problems as well as aggressive because I wasn't responding to him because I didn't feel comfortable with him ... I had a real battle with the psych services in town. The impression of what they were seeing from me was completely opposite from what I was trying to tell them. ... he's got the impression now that I am the one is the trouble maker."* (P8)

The lack of support from professional health workers acted as a catalyst that worsened P8's psychological and physical wellbeing.

*"so I can't open up anymore to them, that's why I pulled out of that support."* (P8)

P8 believed the extended battle she had trying to convince her psychiatrists of the reality of her pain rather than depression acted to exacerbate the severity of her physical and psychological conditions.

*"I was getting depression drummed into my head 'it's depression all the time causing all your problems. If you snap out of that, you'll come RIGHT'. I kept telling them it is the PAIN that was causing me to FEEL the way I was, it was just a constant battle and that's what made me worse, ESPECIALLY, when they said I was SECTIONED."* (P8)

P1 reported undergoing several psychiatric counselling sessions after reports by her medical practitioners that she was neurotic.

P8's doctors concluded her poor physical state was a result of an over prescription of drugs that induced a withdrawal state upon removal of medication. Because of the unsuccessful course of medication, P8 suffered from psychological distress. The failure of medication and unsatisfactory management of her condition led P8 to require psychiatric treatment.

*"Trying some new drug on me and it didn't work for two days and again, I got upset so I ended up in the Psychiatric Ward for another three days down there."* (P8)

P2, P4, and P8 sought resolution and relief for their pain from physical and manipulative treatments including physiotherapy, acupuncture, and/or chiropractic treatment. Unfortunately, these treatments offered no relief and, in some cases, exacerbated their condition:

*"Physio never has helped much. ... It did that [minimise pain] occasionally and it will come back again. ... I have a bit of chiropractor treatment, it made it worse."* (P2)

*"I wasn't coping with muscle strengthening programme. I would suffer unduly afterwards, pain all over. It worked the opposite. ... tried acupuncture and I went through the same thing. All the electrical impulse stuff is not working with me."* (P4)

P6 experienced a nervous breakdown in response to marital failure, while P8 suffered from severe depression due to continuous pain. Both reported attending a psychiatric institution, which did not improve or stabilise their FMS condition:

*"I went to Manawaroa for a while, I didn't like them. They make you feel worse."* (P6)

*"I've been out of Manawaroa about three of four times for the depression. But I am still in pain. I keep saying it's PAIN it's causing, but they say there was nothing there!"* (P8)

These patients suggested that ineffective prescriptive medications and manipulative treatments acted as a catalyst, which exacerbated their FMS symptoms. The unsuccessful medical interventions may have been due to the unknown aetiology of FMS.

On the other hand, FMS patients reported that accurate diagnosis and information (P2, P3, P8), adequate and appropriate medication (P6, P7), treatment (P7), and attentive medical practitioners (P4, P6, P8), contributed to a reduction in their physical and psychological disturbances. Participants' moods and states of wellbeing tended to improve and they reported being generally more co-operative.

*“get a bit of understanding, may help me better because it's finally a name and the symptoms I've been having do correspond ... my depression is getting a little less.” (P8)*

*“The depression would always be there if I wasn't on the Prozac.” (P6)*

*“didn't get rid off the pain. The acupuncture did fix the circulation, because the whole leg was blue when I started going there.” (P7)*

*“I've moved to another doctor, who is much more sympathetic and inclined to listen to me and referred me on to what I need to do. ... He agreed. He believes it exists.” (P4)*

*“I went to Dr. ... privately and that's when things started to get moving.” (P6)*

### **[New Finding]: Professional Misconceptions**

Not only were patients burdened with public misconceptions, but also suffered from the doubtful attitudes of their general practitioners and other health professionals. Both P4 and P5 had limited knowledge of FMS due to their medical practitioners' disbelief in its existence (P4) and lack of interest in their patient's condition (P5).

*“I have a problem and it obviously going to be life long. I want to know about it. But, if he [P4's doctor] doesn't believe it exists, how am I going to find out what I need to know.” (P4)*

*“He didn't explain it very well ... in medical speak and I couldn't understand it.” (P5)*

## **INFORMATION & AWARENESS INTERVENING CONDITIONS**

The information & awareness intervening condition may be defined as knowledge obtained from publicly available sources that participants seek in order to help them understand and possibly mitigate their condition. This category was subcategorised into Active and Limited Information & Awareness. The active information and awareness intervening condition referred to participants' deliberate actions to seek and obtain advice and informational material on the FMS condition. Two distinct paths of gaining and maintaining awareness of the condition emerged. Self-research (P3, P8) allowed patients an opportunity to become 'experts' in their condition, while self-monitoring (P5) allowed patients to use their symptom status to manage their conditions. Both paths directly and positively influenced individuals' propensity to seek medical care and thus influenced the medical intervening conditions. This in turn affected their physical and psychological wellbeing.

*"I got through all the books from the library to find out as much as I could about it. ... Perhaps my depression's getting a little less because I've been told about FMS.... has made me understood some of the things that has happened."* (P8)

*"As soon as flu happens I go to doctor and get prescription. ... I keep an eye on my nose and if I blow my nose and end up with yellow gunk, then I go to the doctor."* (P5)

Limited information and awareness may be defined as inhibitory sources of advice and/or materials participants encounter, which created confusion, clarified little, or provided limited or no explanation of their condition. Lack of access and knowledge about FMS condition (P2, P4, P5, P8) or being provided with inaccurate counsel (P8, see Medical Intervening Condition, pp 82-83) served to worsen FMS patients' physical and psychological wellbeing. For example, P2 identified neglected ergonomic adjustment of her workstation to have contributed to her contraction of FMS.

*"the lack of knowledge of correct work stations. Sitting correctly."* (P2)

*"There's not much out and a lot of it is in the arthritis books."* (P8)

Different medical practitioners often had inconsistent diagnoses of FMS patients' symptoms, with the most common explanation being musculoskeletal pain. These inconsistencies tended to confuse FMS patients and heightened their (P2, P8) scepticism towards the medical profession, causing patients further psychological stress and physical deterioration. These incongruous diagnoses and contradictory interpretations from various medical practitioners led P8 to doubt her own beliefs and brought additional psychological hardship. The outcome of this was that she settled on the explanation that she was depressive.

*"They said arthritis in the lower back. But the rheumatologist said this is FMS, so I don't know."* (P2)

*"My chiropractor's completely in disbelief of FMS. His X-rays show that and the hospital X-rays don't. ... gives me doubts of myself. Because I KNOW I'm in PAIN, has been constant for eight years. ... It does put doubts in you when you're hearing two completely conflicting things. ... you expect the professionals are the ones to go by. I am still up in the air."* (P8)

P8 identified another source of limited information and awareness. She had not received financial assistance due to not being informed by the authority of her eligibility, which increased the financial burdens for her.

*"When the accident happened I was told NOTHING about what I can claimed for. It only happened three years later I was told I could apply for disability allowance. I could've got qualified for a bulk funding then. ... I only found out about this through one of the ladies' daughter." (P8)*

## **SOCIAL SUPPORT INTERVENING CONDITIONS**

The social support intervening condition may be defined as a pattern of relationships, which provide 'social comfort' for an individual in terms of encouragement, understanding, and advice. This category was subcategorised into Occupational Intervening Condition, Support Intervening Condition, and Social Aspects. One participant (P8) who has *"got no support person at the moment"* alluded to her attempt to seek group help from the Arthritis Foundation, but found the level of support to be unsatisfactory due to the infrequency of support-group gatherings.

*"FMS support group, only meet once or twice a year. I wake up in the morning hope to get through the day and think perhaps tomorrow might be different." (P8)*

Work location (P2) and workload (P2, P8) of occupational intervening conditions both created additional physical distress for these FMS participants.

*"in Wellington, job's pretty stressful. PN more low key. ... When I get home, I flop." (P2)*  
*"at night I do collapse." (P8)*

The type of work that FMS patients' were typically impaired in, carrying out, or excluded from performing was of a physical and repetitive nature. For example,

*"So the jobs I do have been travelling jobs ... But the CAR, the driving in itself was really difficult, but I've just changed cars and the last car I had was 21 years old so it had no power steering. It was a very heavy car. ... I am not sure whether it was because I went from a lot of exertion in my upper body to very little exertion in my upper body. ... Yeah [holding arms up for a very long period of time]. ... It is the STEERING, it's actually the upper body that's in severe pain, but the legs are in there too. ... Yeah. It's just a constant barrage [shifting gear]." (P1)*

Work colleagues' and supervisors' insufficient understanding and therefore lack of social support for co-workers with FMS placed a high degree of physical and emotional stress on P2. An unsupportive supervisor exacerbated P8's physical state and depressive symptoms.

*"they weren't very understanding. The boss more so. Cleaning the office was expected even I've mentioned prior I had neck and wrist pain at the interview."* (P2)

*"went through extra stress because I had a real battle to prove my team controller didn't do his part. ... a lot of stress to improve the safety standard of my team controller."* (P8)

Although not in employment, the youngest participant (P3), who is still at secondary school, experienced inconsistent levels of social support from the school staff.

*"some are, some DON'T GET IT. NEVER HEARD of it, obviously doesn't exist."* (P3)

Waylonis et al.'s (1994) study on the effects of the occupational environment reported that some vocational activities can aggravate the symptoms of FMS. For instance, word processing and computer work, prolonged sitting and bending, prolonged standing and walking, stress, heavy lifting and bending, and repeated moving and lifting. There is a resulting tendency to assume that the onset of the various soft tissue symptoms of FMS are due to vocational activities or physical trauma. These job-related motions may also predispose the employees to repetitive strain injuries (RSI), or occupational overuse syndrome (OOS). In addition, environmental and emotional stressors – such as working night or rotating shifts resulting in disturbed sleep pattern, cold and drafty indoor workplace – also tend to aggravate the symptoms of FMS.

The general social misperception of FMS as a 'phantom condition' arises from FMS's physical invisibility and the lack of public awareness. Six participants (P1, P3, P4, P6, P7, P8) believed the invisibility and lack of FMS recognition resulting from social misunderstanding and poor social support were primary contributors to their immediate FMS condition.

*"It's not RECOGNISED! You don't LOOK SICK.... People can't see pain."* (P1)

*"With what you can't see, they don't UNDERSTAND, they think you're all right."* (P6)

*"Their reaction made me question myself 'perhaps it's all in the head, it isn't always in my ears, I loose it all', 'perhaps I am not aching at all, I am just a bloody wimp'."* (P7)

P4 believed that in order for one to understand and sympathise with the FMS condition, the experience of chronic pain was necessary.

*"There is not a lot of understanding. The pain is relative. You can understand to an extent. But if you never ever had chronic pain symptoms, you just can't know."* (P4)

Both P1 and P7 felt that the hardest part of FMS's lack of public recognition was that non-sufferers found it hard to understand or empathise. P7 considered such insensitivity was more traumatising than enduring physical debilitation.

*"They don't understand. That's the WORST thing. ... any honest human being would admit when they are down and out, like sympathy. But you don't get that for something you CAN'T SEE. Because it doesn't really exist! Yet it was diagnosed in 1816."* (P7)

Parallel with FMS's poignant terminology as the *invisible disability* (Raymond & Bergland, 1994), participants generally looked healthy. Most policy makers and service planners therefore believe the severity of pain and the degree of disability shares a significant correlation without it being a life-threatening concern.

FMS patients could typically see improvement in their condition when they received social support from family and friends in seeking information about FMS and their encouragement in seeking medical consultations. Medical-care communication is another source of information gathering.

*"mum got some stuff on work. ... friends, they have internet, to look up stuff for me. ... another fibro patient, I know her and she found quite a lot of stuff on the internet."* (P3)

*"He (husband) was the one tried to get me to see about it."* (P6)

*"The Arthritis Foundation gave me something from the internet."* (P8)

For further discussion on social support (refer Chapter Eight for Coping Strategies).

In the present study, all participants discussed having specific needs: to be understood, to be able to modify and regulate their activities, and to have others' expectations of them readjusted. They also outlined specific concrete needs such as help in getting around, help with housework and other chores, and help with their treatment interventions.

Although the literature indicates that society is beginning to take notice of FMS, it is still largely ignored or disregarded by many, instead falling into the category of "unseen" syndromes. To some, it is just a "yuppie" disease, fanciful and unwarranted, a "catch-all" word when nothing can be found, or worse, an "all in your head" syndrome (Yunus, 1994). Regardless of the empirical evidence of impaired motor functioning (Henriksson et al., 1992) and psychosocial difficulties (Raymond & Bergland, 1994), patients with FMS have been frequently incriminated as "advantage takers". Misconceptions include taking unentitled privileges include over-utilising of health care and financial support, taking excessive sick leave, and limiting activities in the workplace and at home. These types of public and professional attitudes have lead many FMS suffers to feelings of being misunderstood, with a general decline in patient wellbeing. Similar to Raymond & Bergland (1994) a lack of validation and

misunderstanding for patient FMS from their families, friends, employers, colleagues and health-care professionals often intensified psychological stress, lowered self-esteem, instil negative feelings, despair, and alienation. Likewise, subjects in the present study reported a similar pattern to Kelley & Clifford's (1997), where the provision of a diagnosis helped patients to "label" their condition in a way that acted to validate FMS for the participants.

#### **[New Finding]: Bureaucratic Misconception**

The present investigation uncovered a new intervening condition in the form of ACC's disbelief and doubt. The effects of this bureaucratic perspective influenced public policy and ultimately affected decisions concerning compensation and financial aid. For instance, ACC's policies, which by questioning the causation and compensationability of FMS invalidated the existence of FMS, created participants (P3, P4) with stress about their conditions being FMS. (CR Finance Effects, **p.151-152**) For instance, P3 was discredited for her youth and outward healthy appearance, while P4 would never claim for reimbursement under FMS because ACC would not pay compensation.

*"being so young and getting FMS makes ACC QUESTION whether I ACTUALLY HAVE it or NOT, that's hard 'cos they don't want to accept that because I am so YOUNG. ... I've had ACC on my back for quite a long time hassling me."* (P3)

*"I've never claimed FMS for ACC. My claim is still for my back and neck. ... under the same situation as the OOS patients and they'd be looking very serious."* (P4)

ACC's persistent belief that participation in work would improve P1 and P4's condition placed a burden on these two participants. P1 disagreed with ACC's work-benefit theory since she suffered increasing pain as a result of work and knew from experience that her physical state would decline if she returned to work before recuperating. P4 reported similar effects to P1, somatic discomfort and emotional disturbance resulting from her dealings with ACC.

*"they believe WORK will actually help you get better. I am a little bit quandary about that. Because it's actually WORK that makes me sick. ... if I get back to work before I am actually up again I am gonna end up crashing AGAIN."* (P1)

*"They (ACC) are looking at putting me back to work scheme, which after 3½ years, is a wee bit daunting. I was really sore about half an hour afterwards."* (P4)

### **[New Finding]: Additional Social Misconception**

P1 said that gender bias and problematic social aspects have further prohibited herself from managing and improving her physical and psychological states. She mentioned that personal hardships through social ridicule on issues like gender bias, ethnicity, marital status (single), divorced parent, and academic achievement, all continued to affect her health:

*"I belong to a lot of minorities. I am a woman and there is no nation for that. I was brought up with Maori shame. It's actually painful. Then I was uneducated, single mother, and divorcee. Don't own a home and I am 36. All those things contribute. I am improving myself, but it's a battle. ... I am second class citizen, disrespected, ripped off, lied to, cheated. ... you are battling alone, you get no understanding, no help."* (P1)

## **DISCUSSION**

In addition to the variable onsets of FMS, there are a number of aggravating factors, which can lead to functional disability and psychological distress. For example, weather changes, cold or dampness, humidity, stress, disturbed sleep, and inactivity – including working in prolonged isometric positions – particularly with the arms and shoulders fixated (Kalyan-Raman, Kallyan-Raman, Yunus, & Masi, 1985; Hagglund, Deuser, Buckelew, Hewett, & Kay, 1994; Waylonis et al., 1994) all affect FMS sufferers. Other variables – job dissatisfaction, ergonomic arrangements concerning the use of advanced technology at the workplace, bad publicity, medical practitioners' insufficient FMS knowledge about FMS, lack of investigation, and multicultural dynamics – were reported as potential determinants of an FMS epidemic (White, et al., 1997). Finally, factors such as stress, infection, and over-exertion caused symptoms to fluctuate in severity. These findings indicate that FMS patients do not respond typically to physical or psychological stresses. They suggest that the anomalies in the human pain system could correlate with clinical reports that FMS symptoms are aggravated by psychological, physical, environmental, and vocational stresses.

Heightened sensitivity to external stimuli was reported by the majority of the preliminary research findings (Bennett & Jacobsen, 1994, Copenhagen Declaration, 1992, Hagglund et al., 1994, Kalyan-Raman et al., 1984, Lautenbacher et al., 1994, Simms et al., 1988, Waylonis et al., 1994, and White et al., 1997). These aggravating

external stimuli included physical pressure, electrical current, vibrations, humidity, weather/seasonal variations, time during the day, stress, level of physical exertion and inactivity, as well as work-oriented issues, which support the findings from the present study

In summary, insufficient social support and social misperception impinged upon participants' physical and psychological states. Because of the financial burden and limited sources of information and awareness of FMS condition and pain, participants were, in effect, prohibited from seeking adequate medical counsel, which further worsened their conditions and pain. Severe, continuous pain caused participants to seek means of easing their conditions, which, in turn, caused numerous complications and further pain.

CHAPTER EIGHT

**The Coping Strategies**

This chapter explores the axial codes and categories generated from the data and appropriate for inclusion in the paradigm model as ‘coping strategies’. There are six general sections related to coping strategies: cognitive coping strategies, behavioural coping strategies, cognitive-behavioural coping strategies, psychological interventions, family and social support, and perceptions of emotional states. Although each of these sections is dealt with separately in the following report, there is considerable interrelation among them. The following table is a list of coping strategies participants in this study reported to have adopted.

COPINGSTRATEGIES		
COGNITIVE	Cognitive Resolution	
	Non-defeatist Attitude	
	Positive Deferral	
	Positive Self-talk	
	Relaxation	
	Imagery	
BEHAVIOURAL	Consulting Medical Practitioners	
	Behavioural Adjustment	Ergonomic relief
		Frequent movement
		Continuation with activities
		Exercise
		Continuation with activities
		Lifestyle limits
		Limitation of physical contact
		Being in control and/or monitoring
	Physical Interventions	Self-prescribed medication
		Self-prescribed physical interventions
		Active information seeking
		Self-management

COGNITIVE-BEHAVIOURAL	Distraction Strategies
	Attentional Strategies
	Intentional denial/Avoidance Strategies
	Journal Keeping for Relaxation
FAMILY & SOCIAL SUPPORT	Seeking Help
	Spouse Support
	Support Network

**Table 2. The four categories of FMS sufferers’ coping strategies**

The literature on ‘coping’ and chronic pain interprets ‘coping’ as both an active and passive process. The present chapter will focus on active coping strategies adopted by chronic pain sufferers to moderate the symptoms and stressfulness of their condition. In general terms, coping strategies can be thought of as a ‘network’ of mechanisms which aid the individual in dealing with his/her social and physical environment in a manner that mobilises resources to manage stressors (Chaplin, 1985). Specifically, coping strategies are patterned behavioural and cognitive response techniques used by an individual to aid in the management of illness stressors (i.e. such as pain) and avoid or mitigate the harmful consequences of illness. Coping is an aggregate of complex behaviours, which is influenced by an individual’s personal and situational resources, the expectations of consequences, and the properties of the situation encountered (Horn & Munafo, 1997).

**COGNITIVE COPING STRATEGIES**

Six categories of cognitive coping strategies in response to pain or to prevent pain from occurring or aggravating were derived from the data: cognitive resolution, non-defeatist attitude, positive deferral, positive self-talk/attitude, relaxation, and imagery. Each of these is discussed below. In addition, there is a discussion emphasising the relationship between the findings of this study and theories of ‘self-efficacy’.

**Cognitive Resolution**

Participants indicated that their thoughts of pain enabled them to cognitively-manage their severe pain episodes. Participants typically thought retrospectively of events and/or

behaviours that tended to improve or inhibit their FMS symptoms. The outcome of this process was that participants credited causation and exacerbated pain to prior activities alone, despite their awareness of the pathological process and, in this sense, they were able to reach a 'resolution' about their pain through cognition alone. Participants perceived prior physical-activity level to be the dominant causal factor of their condition and health status. By attributing a known occurrence or activity as the cause, participants could then work to alleviate their condition by modifying their activities and behaviours. Therefore, this belief allowed participants to rationalise their symptoms as something that could be controlled. Cognitive resolution is typically an antecedent to behavioural adjustments (frequent movement, stopping and resting, continuation, self-imposed lifestyle limitations) and physical interventions (self-prescribed physical interventions and seeking help). Participants (P1, P4) engaged in retrospective reviews of tasks in order to determine which activities aggravated pain, or to adjust behaviours through a course of repeated experiential-learning. The aim of cognitive resolution was to uncover techniques, which prevented or mitigated pain.

*"I know certain ways to treat my body when I am feeling REALLY sore, when there is a lot of pain. ... You've got to LEARN what IS good and what isn't. Unfortunately that takes a bit of learning. It takes a bit of time too." (P1)*

*"It (pain) can change, even half an hour to half an hour. And sometimes there seems to be no reason, but when you think back, it will often be something you did yesterday or even the day before that's affecting you now. ... If there is a problem coming I know about it more quickly and I pinpoint it to what it is more quickly." (P4)*

In summary, cognitive resolution enabled participants to develop their own knowledge of causes and factors that exacerbated the symptoms of FMS. Moreover, patients learnt to modify their daily activities in order to prevent and/or eliminate pain, and initiate strategies to relieve symptoms and pain. Cognitive resolution showed close associations with the behavioural strategies of regulating activity and physical intervention, and with the cognitive-behavioural strategies of distraction. Cognitive resolution was a pivotal strategy in participants' desensitisation to pain.

### Non-defeatist attitude

Six participants (P1, P2, P4, P5, P6, P7) reported their use of a non-defeatist attitude towards FMS. Participants who relied on this strategy continued with life despite the presence of constant pain. Specifically, these individuals tried to not allow the pain to control their lifestyle and activity levels.

*"If I've got a headache, I can go to bed if I can't I take painkillers. I TRY VERY HARD to not let it stop me doing as much as I can. ... I wouldn't allow myself to worry about it and that sort of worked. ... It's one of those things, you get on with it."* (P5)

*"There's only two alternatives. There's life and there's death and at the moment I've got life, I am gonna keep it. ... I tend to believe the only one who can help is me."* (P7)

The non-defeatist attitude was related to the participants' need to master their pain. Participants indicated a need to partake in a normal lifestyle, and described a non-self-defeatist strategy, a kind of cognitive adjustment, as a means to tolerate pain. This category has not been previously identified in chronic pain studies.

Some participants, rather than ignoring, used minimisation of pain. That is, participants disguised severe pain with a lesser degree of pain to minimise their pain sensations. Typically, this strategy was used after a period of pain. Exposure to pain also caused P5 and P8 to continue with activities. Continuing working did not always suppress the pain since participants often over exerted themselves to a point where their pain defences were inhibited:

*"But if I've got pain I just keep going, but then that made things worse by the end of the day. Because I've tried to do more than what I normally would usually handle."* (P8)

*"I tell myself that it doesn't hurt."* (P5)

*"in a lot of pain, I say 'it's all in my mind' and try to keep going. ... go to bed at night and try to tell myself pain is not THERE, I KNOW it was THERE, it was so hard."* (P8)

Participants' use of this strategy also supports findings by Newman et al. (1990). They studied people's attitudes toward their rheumatoid arthritis and idiosyncratic coping strategies in relation to the level of disability, perception of pain and joint stiffness, and psychological wellbeing. They concluded that people who dealt best with these factors made minimal changes in their everyday lives toward their illness and did not attempt to use Intentional denial, social support, or self-distraction to cope with illness.

### Positive Deferral Strategy

Two participants (P5, P7) adopted a kind of positive deferral strategy. This strategy involved the ‘movement’ of pain impacts and causality to life activities and events over which participants had more control. Through this strategy, the causes became more salient to the patients and therefore more controllable. In some respects, this strategy is similar to cognitive resolution, but differs because, here, participants only relate their symptoms to a cause instead of actually applying any ‘real’ intervention to relieve symptoms. Rather, participants blamed or deferred their pain to factors other than what it actually was. Like cognitive resolution, positive deferral strategy does rely on a strong level of self-efficacy if participants are to successfully defer their pain to a non-causal factor.

*“I just put it down to everything else that was going on at the time. ... ‘I overreacted to a joint injury’, which is how it’s explained to me that my joint’s overreacted.” (P5)*

*“see someone in a wheel chair and think ‘if he has sex, he wouldn’t want to lift on top, at least I can still CLIMB on top’! That might sound cruel, but I’m not meant to.” (P7)*

P5’s explanation of the injury as an ‘overreaction’ allowed her to assume that what caused the injury was an overreaction and therefore was controllable. P7 used the comparative technique: *“I am better off than somebody else”*, which made his experience more positive by deferring negativity onto someone else. P7 deferred bad feelings or impairment onto someone else to allow him feeling better about his own. In this light, both the positive aspect (i.e. the feeling better) and deferral were mentioned. Both techniques were positive deferrals because P5 deferred the cause in order to feel more in control while P7 deferred bad feelings onto someone else to allow him feeling better.

In some respects, this strategy is similar to cognitive resolution but differs because, here, participants blamed or deferred their pain to factors other than what it actually is and so it does not lead to any ‘real’ intervention to relieve pain.

### Positive Self-Talk/Attitude

Participants described how the long term suffering of FMS symptoms has lead to a gradual desensitisation that was reinforced with self-advice. For instance:

*“I never see the end of the road. I would go through the adjustments. Be positive. Make the best out of it. My greatest advice is ‘DON’T GIVE UP! Don’t presume that’s what’s gonna be for the rest of your life. Become the master of it’. You work around it.” (P1)*

*"KNOWING that they can AT LEAST DO SOMETHING. Like the exercise. ... more aware of the rehabilitation process, so that's been quite positive for me." (P2)*

*"Shit happens, you can't change it. You only wipe it. I manage. 99.9% of people COPE because you have to." (P7)*

Assuming a positive attitude helped participants believe in their ability to manage their pain. The acceptance of chronic pain and the associated symptoms of their condition was an important step towards developing a positive attitude. Participants' ability to continue with daily activities, regardless of the severity of pain sensation, appeared to be a result of the application of a positive attitude, acceptance, and increased tolerance for pain.

Positive self-talk refers to a motivational technique that has been successfully used to combat chronic pain (Bloomfield et al., 1992). In effect, positive self-talk refers to the restructuring of the patients thoughts and beliefs towards a more positive productive mind-set through the use of internal dialogue when stressful stimuli are encountered. When coupled with other motivational techniques, positive self-talk can help the patient to more effectively deal with their symptoms by allowing behavioural strategies to be applied more successfully.

## **Relaxation**

An attempt to use relaxation technique was made by some participants (P4, P6, P8):

*"I use relaxation exercises when I remember." (P4)*

*"I have a hot bath. I've got to turn the light off. Sometime I find that's soothing and relaxing. ... I am making sure that I am relaxed, well, try to relax." (P8)*

Relaxation reduces the muscle tension that contributes to pain and facilitates pain management by moderating the sympathetic nervous system functions that are usually activated by stressful situations and conditions. Relaxation therefore helps to conserve vital energy required to promote healing and fight discomfort and disease (Turk et al., 1983, cited in Bloomfield et al., 1992).

## **Imagery**

One participant (P4) used visual imagery, in which she directed her thoughts to a remembered pleasant place. This strategy had a relaxing and distracting effect from the pain that helped her to function more normally. In addition to imagery, P4 would lie down and

rest. She later discovered how her endurance for physical activity seemed to be enhanced through such techniques.

*"It was the beach I grew up at. My headache and pain in my body was at one of its lowest levels. Because I love the place. When I am relaxing, it's THAT place I visualise. And I was actually there, I was ABLE to DO MORE. I walked longer distances."* (P4)

This visual imagery strategy had a similar effect to the distraction technique in that both work by diverting the participant's attention from their physical state and pain. This participant alluded to the effectiveness of such strategy because it stopped her from thinking about the pain and helped her relax.

Imagery or visualisation is an important component in pain coping (Copp, 1986). The "imagination" can be used to facilitate the rehabilitation process, particularly when used in conjunction with relaxation exercises (Bloomfield et al., 1992). The imagery used by P4 would be classified as *incompatible imagery* (Neumann et al., 1997). Incompatible imagery requires the imaginations of events, feelings, and sensations that are incompatible with pain. The significance of incompatible imagery is its ability to prolong the duration people are capable of tolerating pain. Imagery improves pain tolerance and can change one's psychophysiological responses to pain.

Imagery was used by only one participant in this study, which is contrary to Copp's (1986) theorising that imagery is a prevalent pain coping strategy.

## DISCUSSION

### Cognitive Coping Strategies & Self-Efficacy

Self-efficacy is the conviction and expectation that one is capable of conducting certain behaviours successfully (Horn & Munafo, 1997). Self-efficacy beliefs influence people's levels of stress, depression, and motivation, and also reported pain and coping. Although the data in this study did not generate any clear or obvious category that could be labelled 'self-efficacy', there is evidence which suggests a relationship between this psychological construct and the categories derived from participants' data on cognitive coping strategies.

In a review, Bandura (1977, p. 191) suggested that expectations of personal efficacy determine the initiation of coping behaviour, the effort expended, and the duration for which it is sustained when subjects are faced with obstacles and aversive experiences. Persistence in activities that are perceived as threatening, but in fact are

relatively safe, and progression through experiences of mastery of pain, enhance self-efficacy and correspondingly reduce defensive behaviours. In Bandura's model, expectations of personal efficacy are derived from four principal sources of information: performance accomplishments, vicarious experience, verbal persuasion, and physiological states. The more dependable the experiential sources, the greater are the changes in perceived self-efficacy. In the present context, participants' self-efficacy in relation to their ability to manage pain became the key psychological factor, which enabled participants to cognitively resolve their FMS conditions. In more general terms, participants 'believed' or 'learnt to believe' in their ability to rationalise pain to a controllable causal condition. It was this process that then allowed participants a form of cognitive relief from FMS symptoms and to engage in activities in spite of the pain.

Thompson (1981) suggested that pain that is perceived by patients as beyond their level of tolerance will provoke expectant anxiety and avoidance behaviour. After reviewing studies on the relationship between anxiety, avoidance behaviour, and inefficacy beliefs, Bandura (1989, cited in Keefe et al., 1997) proposed that efficacy beliefs may indirectly impact on pain. High self-efficacy, acquired through "mastery of pain experience"[s] is not a fixed property, but as described by Bandura (1977), it can vary over time and circumstances. Jensen et al. (1991) and Council et al. (1988) established that there was a close association between self-efficacy beliefs and actual behaviour in pain management programmes, and concluded that behavioural interventions for pain might be refined when self-efficacy is accounted for (Keefe et al., 1997). Keefe et al. (1997) illustrated that specific cognitive pain coping strategies, namely coping self-statements, ignoring pain sensations, and reinterpreting pain sensations, were predictive of rheumatoid arthritis patients' self-efficacy beliefs.

In this study, participants' appraisals that they were able to initiate strategies that could effectively control pain corresponded to Bandura's (1977) concept of efficacy expectancy. Participants reported increased expectancy of or belief in self-efficacy over time, as they increasingly mastered coping strategies they had developed. This experience reflects what is known as *personal mastery experiences* (Bandura, 1977).

In terms of actual cognitive coping strategies used by participants' in this study, several emerged as effective in the management of chronic pain, disability, and emotional and psychological distress are common adjuncts to conventional medical and rehabilitation practices. Additionally, various motivation techniques were used for pain management including relaxation, imagery, goal setting, positive self-talk, and

behavioural therapy that partially paralleled the reported use by Bloomfield et al (1992) in chronic pain patients. For instance, motivational techniques were used, but not to the extent as in Bloomfield et al (1992) study. Despite the low prevalence of use, those who did rely on motivational techniques commented on a high degree of effectiveness.

## BEHAVIOURAL COPING STRATEGIES

Three codes of behavioural coping strategies were derived from the data: Consulting Medical Practitioners, Behavioural Adjustment, and Physical Interventions. These codes represented physical behavioural interventions participants reported using in response to pain, or to prevent pain from occurring or being aggravated. Each of these is discussed below. In addition, there is a discussion of the relationship between the findings of this study and literature on treatment interventions.

### Consulting Medical Practitioners

Pain influences the ways in which coping strategies are utilised. In addition, the types of coping strategies used can positively or negatively affect the severity of pain. Typically, participants' first reaction was to seek a medical practitioner's help. Medical practitioners included institutional health-care professionals and agencies whose purpose is to provide individuals with diagnoses and conventional or non-conventional forms of tests, prescriptive medications or treatment, surgery, alternative manipulations, or financial subsidies. All participants attended their doctors repeatedly over a prolonged period for medication or treatment as a result of ongoing diagnostic difficulties (refer Chapter Seven, The Intervening Conditions).

*"Physio treated me for AGES until he gave up and I went back to the doctors and he sent me up to the hospital for physio and the X-rays, blood test, brain scans, and specialist. ... a pretty drawn out process going through so many people." (P3)*

*"two or three days later I developed a headache. I had X-rays and CAT scans and they said everything is normal. I was still in PAIN. ... I went through psychiatrists and became suicidal. ... I've got anxiety attacks." (P8)*

The use of drugs and their effectiveness is often short lived. For instance, *'It's Amitriptyline. They do use it for depression, but the dose I am on is not as much as what they use for depression. ... so I can sleep through the night without pain. ... he'd*

*only start me on 5mg dose and that wasn't really working and he wanted me to gradually get up to 25."* (P2)

*"I am on Amitriptyline to help me sleep at the moment. Yeah, keep on increasing it to try get a wee bit of sleep, to let me sleep through the night, but, so far it hasn't achieved it's GOAL and purpose of keeping me asleep. ... Started like 5mg and now I am up to 30 at the moment. ... I suppose it hasn't proven in quantity, but it has improved the quality of my sleep. ... it's doing something but not a HUGE change. It might BE working."* (P3)

The literature indicates medical professionals are generally hesitant to prescribe medications for chronic pain conditions such as FMS based on the rationale that most drugs are unhelpful if taken over prolonged periods (Ediger, 1991). Despite these considerations, various drugs are used to treat FMS. For instance, Amitriptyline (used by P3), a tricyclic antidepressant, is reported efficacious in treating pain and tender point sensitivity for approximately one month (Carette et al., 1994, cited in Mason et al., 1998). Their efficacy is clinically established in depression and there is evidence that they increase pain thresholds. However, the results vary individually: what works for one person may not work for another.

No analgesic pain medication, with the exception of aspirin or similar drugs, can be used over a prolonged period of time without producing drug tolerance. That is, most analgesic medication must be taken in increasing dosages in order to continue to have any analgesic effect, while unwanted side effects may persist or grow. For that reason, analgesic medications are not recommended for pain, which persists for more than a few weeks (Gildenberg & DeVaul, 1985).

The literature on medication and its effects, while quite thorough, does not address all concerns of patients about their consulting medical practitioners. While there is some attention paid to medication in participants' accounts, most found drugs to be ineffective with the exception of P6 who found Prozac useful for managing her depression. Moreover, most patients raised other issues that have been largely ignored in the literature. For instance, participants expressed primary concern about their relationships with their doctors. Participants also raised the issue of diagnostic difficulties in relation to their treatment. This issue has been discussed in detail previously as a medical intervening condition (Chapter Seven) and will be raised later in relation to satisfaction with medical-care services (Chapter Nine).

## Behavioural Adjustment

The axial code of behavioural adjustments referred to changes in behaviour initiated by FMS patients in response to pain and other FMS symptoms. The purpose of behavioural adjustments are to prevent and reduce the occurrence of pain. Participants who relied on **ergonomic relief** (P1, P4, P6) also exhibited a pattern of **frequent movement** (P1, P4, P5, P6, P8). Ergonomic relief relies on positional adjustments and/or external objects such as special chairs. Both ergonomic relief and frequent movement were used to alleviate pain.

*"When I get severe pain in my leg, I prop them up on a gradual pillow structure, so there is no pressure on my knee. I lie there like that. I put my arms up on high pillows and my head back. So my body was on soft pillows. ... I've propped myself in the right positions where I'm sore so the stress doesn't continue."* (P1)

*"There is a constant movement. I try to have a balance of activities. ... I try not to sit, walk, and stand for too long. ... I try to move quite often to keep the muscles from locking up. Walking around or swaying. Flicking my arms or moving my feet. Gentle exercises. Even five minutes is enough. ... At home, I'd go out and have a little walk around the garden or I'd find something to read or do. ... I move my head a lot."* (P4)

Maintaining some form of physical **exercise** was another type of behavioural intervention described by participants (P1, P4, and P8) that helped in the management of pain. Apart from the usual respiratory benefits, exercise was described as an effective way to eliminate muscular stiffness.

*"Exercise when necessary. It means just pushing myself a little bit further. ... Exercise for me is hanging out the washing."* (P1)

*"I am walking a lot.... I BIKE whenever I can."* (P8)

In addition, participants described **stopping** their current activity and lying or sitting down (P1, P2, P6, P7, P8), and taking medication (P2, P6) as a means to relieve pain. Participants' application of such strategies was related to the severity and habituation of their pain, their level of social engagement, prior learned experience, and their desire to complete the current task. Participants commonly experienced a trial and error learning process in order to determine their pain threshold required to participation in an activity.

*"Just drop everything and go and lie down on the couch and go to sleep or just rest. ... I try and rest e-v-e-r-y-d-a-y and if I am really sore, since I've had Prozac, I've relaxed more so if I rest, I might quite often sleep and when I wake up, I feel a lot better."* (P6)

Alternatively, not allowing pain to interrupt daily routines was based on participants' belief that pursuing activities could circumvent pain to a certain degree. Decisions to continue with activities were contingent on participants' previous experience, with a degree of anticipation that pain severity may be alleviated by maintaining an activity. These strategies were used in combination with other cognitive and cognitive & behavioural strategies. For example, five participants (P1, P2, P5, P7, P8) believed that **continuation with activities** also acted as a source of distraction from pain. P7 pursued tasks in combination with stopping and resting phases and/or ignoring pain. Activities were typically goal-oriented, for example:

*"was still at work, just wasn't well... not let it stop me doing as much as I can." (P5)*

*"To the hell with it. Get the walking stick. I stop and sit on the fences. ... The only thing I have great problem with is vacuuming, because the movement of the shoulders. It just takes me longer. The noise of vacuum cleaner DRIVES ME MAD. I ignore it." (P7)*

Two participants chose to continue with socially-oriented activities to avoid social isolation and maintain a social network despite the severity of pain.

*"I try not to be that different. ... I pushed myself too far going to this ball." (P3)*

*"with my knee, if I am sore and I want to go out, 'well, bugger it, I'll go out'." (P5)*

Sufferers' awareness of alleviating action(s) against conditions and pain were evident in various forms of behavioural adjustment and other coping strategies that encouraged participants to believe that they could manage. This resulted in further positive and non-defeatist attitudes, as well as self-efficacious feelings.

Four participants (P1, P4, P5, and P6) attempted to maintain their lifestyle by imposing **lifestyle limits** in order to prevent pain from occurring. These lifestyle limits generally involved restraints to physical mobility (P1, P4), monitoring of personal health (P5), and avoiding of psychological distressing stimuli (P6).

*"I don't do the things I know that are going to damage me." (P1)*

*"I try to avoid situations where I am likely to get knocked or walked into or bend." (P4)*

*"I DO notice when I am not comfortable. If it's upset, I try my own herbal side to get away from antibiotics and doctors." (P5)*

*"Avoid stress if I can and have plenty of rest. I know my limitations and what to avoid so I won't get into a stressful situation. I know to do things when I'm ready." (P6)*

Most participants (P1, P2, P3, P4, P5, P6, P7, and P8) stated a need to limit their activity in order to relieve and prevent further pain. That is, being “*painful*” was typically the reason for participants limiting their physical activities.

*“It restricts your exercise.” (P1)*

*“from able to play fight with my husband to not anymore ... where I have to maintain a position for any length of time ... Walking distance causes problems. ... biking is too painful.” (P4)*

Two participants (P2, P7) concurrently described difficulties with writing and their precision grip (i.e., holding a pen). Consequently, both had to minimise the use of their wrists and gripping. Alternatively, when tasks such as writing were unavoidable taking periodic rests became necessary (P7).

*“... Writing, I haven’t been able to do long length of time.” (P2)*

*“Do a lot of writing. Just take a lot of breaks.” (P7)*

Typically, sufferers required numerous micro-breaks during or between activities, particularly with repetitive tasks and tasks that maintained a fixed position for sustained periods (Henriksson et al., 1992) as well as occupations with high stress (Waylonis et al., 1994).

Three participants (P1, P4, P6) adopted **limitation of physical contact** as a strategy to avoid pain. The side effect of this strategy was the mitigation of opportunities for intimate relationships and/or physical signs of support. P1 further specified her learned strategy to avoid physical contact by initiating it during social interaction, thereby controlling the amount and type of touching.

*“I have a safety zone. It’s a sensitive zone. I don’t like to hug and don’t quite often like to touch. I’ve learned a technique to touch them on their hand or arms ... I would be talking to them and then I pull back. We don’t have any close contact after that.” (P1)*

*“There’s no way I’d ever let anybody touch me. No way!” (P6)*

Finally, two participants considered **being in control** (P4) and/or **monitoring** (P4, P5) their FMS condition was most effective for pain relief, while P6 was able to handle her condition more effectively being left alone:

*“Being in control of my situation. ... Monitoring FMS is attempting to do things to keep my muscles relaxed.” (P4)*

*“I like peace and quiet, to be left on my own. I find I can get over it quicker.” (P6)*

Participants' sense of control and capacity to manage their conditions and pain were consequential to behavioural adjustment and pain relief. The behavioural adjustment strategy preceded cognitive and behavioural strategies, which served to divert participant's attention from pain and cognitive strategies, which addressed pain. After participants coped by stopping, lying down, and/or adopting a form of physical intervention, they applied a form of distraction and/or positive attitude, which will be discussed later.

In summary, the axial code of behavioural adjustment consisted of the substantive codes of ergonomic relief, frequent movement, stopping and resting, exercise, continuation with current activity, self-imposed lifestyle limits, and self-imposed limitation of physical contact. Participants attempted to maintain a balance between continuing to engage in daily activities, while tolerating a degree of pain induced through activity. Activity was discontinued when pain severity became unbearable, tight, or if they knew they had reached their limits. They typically assessed their physical limitations through trial and error as part of the experiential-learning process, beginning relatively soon after the onset of their conditions. Participants were consistent in that this group of coping strategies developed as they obtained knowledge of pain management strategies and a sense of control over pain.

Not only did the present investigation provide support for previously suggested behavioural coping mechanisms, but also identified the recorded behavioural adjustment coping mechanism.

### **Physical Interventions**

Due to their non-defeatist attitudes, these participants continued to help themselves through trying and self-prescribing physical interventions to ease pain and other FMS symptoms. In addition, they received prescribed medication and/or physical treatment from medical-care practitioners. Among the behavioural strategies, these participants used three strategies that were coded as 'self-management': Self-prescribed Medications, Physical Interventions, and Active Information Seeking. It appeared that participants occasionally intensified their pain due to unsuccessful trial-and-error learning attempts using self-adopted coping strategies.

**Self-prescribed medication** refers to the use of self-care remedies or herbal treatments (P1, P2, P3, P5, P8) and dietary modifications (P1, P2, P5), which had no support from conventional medical practitioners. Participants' use of alternative medication was a reaction to their desperation to alleviate the severity of symptoms or at least not deteriorate further.

*"I've been taking VITAMINS, goducolas, selenium, vitamin C, vitamin B."* (P1)

*"I am on the supplements at the moment for melic acid." (P3)*

*"I drink ginger tea and I eat food with ginger in it if I get an upset tummy. ... I warm my milk and put Milo in it before I go to be, IF I am having problems sleeping." (P5)*

*"I've been using mainly lavender because that's what they say for headaches." (P8)*

**Self-prescribed physical interventions** consisted of external manipulations, including massages (P1), heat applications (P3, P6, P8), and ergonomically-designed aids (P2, P5), which were described by several participants as an effective means to relieve pain. The process of learning to self-manage FMS condition through physical interventions occurred over time since onset and was part of the experiential-learning process. These interventions were often applied along with resting (P1, P3, P8) or distraction (P6), which offered both pain relief and increased a sense of control over pain:

*"I have got a hand hold massage. It didn't remove the PAIN, but the INTENSITY." (P1)*

*"fill a bottle of hot water, snuggle up to that and relax, watch TV or read a book." (P6)*

*"Arthritis Foundation has got a wider peeler helps to grip your hand." (P2)*

*"I sleep on a special pillow for my back." (P5)*

A specialised form of help-seeking frequently referred to by participants was **active information-seeking**. Participants would gathered FMS information from the internet (P3) and relevant books (P4, P5, P8).

*"I've got stuff off the internet just recently and I found really helpful because they know MORE, it's more recent developments." (P3)*

*"I've taken some books out of the library." (P4)*

Gathering information provided a path to regain control through the advancement of participants' personal knowledge in relation to the course of their conditions and possible remedies to help with pain. Health-care practitioners and institutions were often the providers of information. Several participants (P2, P4, P5, P6, P7, P8) reported receiving information from doctors in addition to self information-seeking.

*"They gave me some papers to read and Dr. ... gave me a book to read. ... pain management programme. One suggestion is you only sleep in for an extra hour." (P4)*

*"He said it's chronic. I since then know chronic means long lasting, not severe." (P7)*

Volunteering to participate in health research or programme(s) was an avenue to collect FMS information for participants. The effect was that participants (P1, P3, P4, P7) seemed to have benefited from knowing about their conditions and having contributed to

the medical professionals knowledge about FMS. Finally, participants appeared to have gathered a sense of encouragement from the researchers' commitment to FMS.

*"Both of us are having tissue types taken for the hospital to do with FMS and because of our being so similar (twins) to see if there's a connection there. It's encouraging because there is hope for you, just looking for cure for it."* (P3)

*"I am trying to fill out something at the moment for the rehab centre and they are looking at numbness and pins and needles and those sorts of things."* (P4)

*"I am not talking to you at all. I am actually talking to a piece of paper that hopefully will help other people. I am not here to share or unburden myself. This is actually making me feel terrible because it's embarrassing and it's mentally painful. ... Today is a good day because talking to you about it is probably the most positive thing that has happened to me since I've had it. Because I THINK you believe it exists."* (P7)

A good example of the substantive code of **self-management** was illustrated by P5, who was diagnosed with FMS five years ago. Both her long-term experiences with the symptoms and her self-monitoring of pain severity enabled her to pinpoint the most suitable line of medication and treatment.

*"If I injure the joints, I go to physio. My neck is constant, I go to physio or osteopath. ... Since 12 or 13, I always carry Panadol or Nurofens in my handbag."* (P5)

P5's successful self-management cognitive coping strategies consisted of ignoring and minimising pain (discussed in detail on page 127). The outcome of P5's self-management was a reduction in both the frequency and severity of her pain experience, which she reported as being down to 'discomfort'.

*"I don't experience it all the time. On a weekly basis there is some discomfort in my shoulders and neck and back. Just uncomfortable. Used to be quite bad."* (P5)

In summary, the axial code of self-prescribed physical interventions encompassed massage, application of heat, taking medication, adequate diet, and use of ergonomic aids. Overall, outcomes for physical interventions shared similarity with behavioural adjustment in numerous aspects, that is, experience and learning, knowledge for managing pain and condition, and sense of control. Participants' perceptions of social support was also affected by seeking help.

## DISCUSSION

### **Behavioural Coping Strategies & Multi-modal Treatment Interventions**

Like most chronic pain patients, participants in this study were motivated to behave in ways that minimise their pain. Within the wide array of available treatments, some of which are medically unorthodox and extreme, patients' coping regime has become the dominant aspect of the chronic pain experiences.

Evaluations of multi-modal treatments for FMS have reported significant, positive, immediate and long-term effects on their psychological wellbeing and pain (Mason et al., 1998). Among the benefits of multi-modal approach to treatment is the temporary alleviation of pain, improved mobility, and reducing muscle tightness (Ediger, 1991). These types of treatments not only reduce the signs and symptoms that characterise the condition, but carry over to improve patient's quality of life and personal wellbeing (Metcalf, 1990, cited in Feine & Lund, 1997). For instance, these FMS participants adopted physical therapy and aerobic conditioning to fight stiffness and easy fatigability in the muscles. Exercise, in particular, has the ability to lower pain intensity and the number of tender points and improve physical endurance and general mood.

Bennett et al. (1996) also found that patients' conditions improved in the long run through the provision of accurate diagnosis, cognitive-behavioural programmes, and aerobic physiotherapy. In an earlier study, Boissevain & McCain (1991) found that FMS may also be mitigated by weather and physical therapy as well as other forms of intervention. Feine & Lund (1997) found a tendency towards short-term improvements in efficacy despite the therapy adopted. Specifically, they found that even placebo treatments show a positive effect on patient efficacy. Patients became less anxious towards the future and paid less attention to pain when they receive both physical therapy and better information.

Parallel with rheumatoid arthritis patients' reports from Blalock et al.'s study (1993, cited in Haythornthwaite et al., 1998), FMS participants in this study who seemed better psychologically adjusted reported using multiple coping strategies within various situational contexts whereas those who were pessimistic and depressive reported the use of fewer strategies. For instance, behavioural adjustments were frequently used concurrently with distractions, which will be discussed in the following section.

However, while there are numerous published studies on the aetiology and diagnostic criteria of FMS, only a few have investigated treatment outcomes, indicating

the need for further research. Despite the lack of literature, a general criterion of treatment effectiveness would include a need to demonstrate a reduction in symptom type and symptom severity. Additionally, an increased sense of control and relief from pain, and an improvement in patient wellbeing and quality of life.

In summary, seeking help resulted in support and assistance with physical interventions, which were typically provided by significant others. Seeking help superseded exhibiting emotional distress when participants became more desensitised and adapted to their pain. The applications of behavioural adjustment and physical interventions empowered participants with feelings of control over the conditions and pain, and a sense of social support. Participants made decisions about behavioural adjustments in response to the context and pain severity. Depending on the situational context, participants would either stop and rest or continue with current activity during severe pain. Continuation with an activity was an intentionally adopted behavioural strategy of self-distraction from pain, and it allowed participants some normal social activity.

## **COGNITIVE-BEHAVIOURAL COPING STRATEGIES**

Four categories of cognitive-behavioural coping strategies were derived from the data: Distraction, Attentional Strategies, Intentional denial/Avoidance Strategies, and Journal Keeping. Each of the four cognitive-behavioural strategies is discussed below. A discussion of the relationship between findings of this study and preliminary literature is drawn.

### **Distraction Strategies**

These were activities participants adopted in order to divert their attention and gain relief from symptoms of FMS, particularly the pain. These strategies involved engaging in a behavioural activity and reflection of the activity's effectiveness. Seven out of eight participants (P1, P2, P3, P4, P5, P7, P8) claimed to use these strategies. Pain severity and previous experiences affected the type of distraction strategies utilised. Participants varied in their perception of the effectiveness of distraction, and their reliance on it as a coping strategy. The strategies participants adopted ranged from watching television and reading books (P7), occupational diversion (P7, P8), having a purpose to do something (P1), continuing with activity (P1, P2, P5, P8), to involving others (P3, P4, P5, P8). Of all

participants, P7 relied most heavily on distraction techniques to mitigate pain, although these strategies had little effect on his tinnitus.

*"Like a really interesting TV programme, a really good book, then the distraction is good enough that you forget about pain for an hour, five minutes. ... Distract myself from it and I DID quite well. So 99% of my FMS I can push it to one side."* (P7)

*"If I stop, I start thinking of the pain, but if I keep busy and concentrate on something, I get through. Perhaps the pain is there the whole time, but I'm thinking elsewhere."* (P8)

Two participants (P7, P8) stated that they benefited from working, which served as a distractor. P8 found **work** helped to keep her mind occupied, which both alleviated and diverted her attention from pain (headache (facial pain) in particular) and reduced the likelihood of further depression.

*"Working's always been very good for the soul."* (P7)

*"I try to keep my work going, because if I stop I would probably find I'd be in a lot more pain and wouldn't be able to even bend over or something. ... when I get home, that's when I can either go to sleep or the depression really hits you."* (P8)

One participant (P1) indicated the need for goal-directed distraction to motivate her towards achieving tasks that served to divert her attention from the pain:

*"When I am on the high, I can FEEL the pain, but I can rub it out. Because there was a sincere, honest, loving purpose for me doing it and I don't complain about it. I can MOTivate. I can talk myself into doing ANYTHING but I can't do it for myself."* (P1)

Of particular relevance to participants who experience chronic pain, the strategy of keeping going served as a distractor, and also functioned to keep them involved and exposed to interactive social activities.

Severity of pain and prior experiences influenced participants' decision as to whether to use distraction and behavioural strategies in general. Participants also initiated a combination of other coping strategies along with distractions. P6, for example, used television, reading, resting, and her spouse's personal assistance as ways to control the severity of her condition:

*"fill a hot water of bottle and snuggle up to that and just relax, watch TV or read a book. ... lie on the couch and I don't have to worry about doing anything because my husband will do it if I want to it done."* (P6)

Distractions involving significant others in socially oriented activities, termed as positive family/friends-oriented coping strategy, were also reported. Seeking support was

typically related to this strategy. Examples included associating with and talking to significant others. This turned out to be an effective distraction for four participants (P3, P4, P5, P8), while also providing additional benefits of social interaction:

*"I'll go up and spend time with Tony at work. ... if I am sore."* (P4)

*"kids being young, busy so I relate MORE to THEM because I like to keep busy."* (P8)

Recent findings (Arntz et al., 1991; Haythornthwaite et al., 1998) reported in the pain literature were directly relevant to the present finding. These authors considered attention-diversion techniques fundamental for psychological treatment interventions for chronic pain patients. In this study, all participants reported using distraction strategies and their increasing expertise at applying these strategies.

An awareness of the cognitive influence on relieving pain was described in all stages of using distraction, although the effect of strategies varied between participants, and participants developed their own preferred distraction strategies. Participants' coping strategies changed over time since onset of their condition and in relation to other contextual variables.

In summary, most participants reported use of distractions through the course of their FMS. Participants' selection of distraction strategies helped them to divert their attention from pain and thus relieve pain severity. In addition to severity and time since onset, personal preferences and situational contexts influenced participants' decisions about which distraction technique(s) to use. Furthermore, the level of interest in the distractor and degree of concentration influenced the degree of relief from pain. However, when pain became too severe, other interventions (such as stopping and resting) were employed in addition to the distraction strategy. Finally, engagement with significant others provided participants with social support in addition to diversion of attention from pain and symptoms.

### **Attentional Strategies**

Two participants' (P5, P6) conditions have shown improvement through their adoption of individual self-management coping strategies. P5 used ignorance and P6 self-monitoring. P5's improving condition was based on the reduced frequency of symptomatic occurrence and severity of pain, while P6 emphasised that the reduced salience of stress assisted the improvement of her FMS condition.

*"if neck goes out, it's very painful. It's only every two months [now]. Otherwise it's just a bit DIScomfort than severe pain in my shoulder. Weekly or fortnightly." (P5)*

*"started to improve. ... I am now out of my stress side because my children are now left home and I am not under any stress so it's made a big difference." (P6)*

Philips (1987) indicated that avoidance is often extensive and complex in pain patients, and encompasses movement, stimulation, activity, social interaction, and leisure pursuits. In contrast, attentional strategies, concentrating primarily on the source of stress through reappraisal and information seeking, had superior long-term effects since more information was uncovered with increased adjustment. This is consistent with preliminary findings (Holmes & Stevenson, 1990; Suls & Fletcher, 1985) which indicate that both strategies can reduce physical and psychological stressors with psychological adaptation and behavioural adjustment within a particular context. Individuals who employ adequate coping strategies are able to manage pain with better psychological, behavioural, and somatic adjustments.

### **Intentional denial/Avoidance Strategies**

Three participants (P2, P5, P7) used pain suppression through 'ignoring'. They reported intentionally *"forgetting about it"*, *"not thinking of it"*, and *"ignoring it"*. This is similar to cognitive technique of thought-stopping. Intentional denial was the first reaction, the initial strategy, and continues to be used by P5. Participants using this strategy consider Intentional denial as a form of pain relief. They described how *'not thinking about it'* helped them to believe the pain was no longer present and minimised the significance of pain.

*"Sometimes you just block it out, just try not to think of it at times." (P2)*

*"AFTER I was diagnosed with it I just forgot about it because I didn't know what it was and couldn't get answers from anybody so I thought 'there's problem with my joints and I overreacted to a joint injury'. I don't think it's anything to worry about. ... I tell myself that it doesn't hurt. I IGNORE it. It takes a while for me for that to work. It normally takes a week or two. But once I get into that cycle, I am quite good." (P5)*

*"IGNORE it as much as I can. I know it's there but it's not important. ... because it exists, I can't take it away so I am not going to make my FMS FEEL GOOD by talking to it all the time and reminds me." (P7)*

These same participants also described information seeking in similar contexts as a strategy to divert thinking about FMS pain and symptoms.

Both P5 and P7 reported a sense of control that was directly related to their ability to “ignore” or “forget about” the pain. There was a relationship between P7’s use (stated above) of this strategy and length of time since onset. He indicated modification in the pain-management process over time when he emphasised that pain “WAS (important) *but not NOW*. ... *I am bloody sure I can’t change it, so why give it any more importance than it actually is*”, that is, he now tolerates pain better.

Avoidance strategies, Intentional denial, and ignoring provide short-term reward since they offer immediate relief from stressors. Philips (1987) indicated that avoidance is often extensive and complex in pain patients. McCracken (1998) stated that avoidance strategies are unproductive for coping with chronic pain as they frequently result in somatic degeneration, impracticably high anticipatory pain during activity, are self-perpetuating, and are predictive of depression and disability. On the other hand, chronic pain patients’ acknowledgement and acceptance of pain can help sufferers to abandon both unhelpful means of pain control and beliefs that pain automatically involves physical impairment. Chronic pain patients who accepted and acknowledged their conditions tended to pursue treatment more often and report lower pain intensity, less pain-related anxiety and avoidance, less depression, less physical and psychosocial disability, improved life quality, and superior work status than chronic pain patients who favoured avoidance strategies (McCracken, 1998).

McCracken (1998), however, described avoidance of activities that cause pain. In this study, participants avoided thinking about pain in many cases in order to continue with daily activities.

### **Journal Keeping for Reflection**

P4 and P7 reported thinking about keeping journal as an update of their condition:

*“Not that I can remember. If I kept a diary, that would be the god thing to do. To keep a diary, but I didn’t.”* (P4)

*“Ringing in the ears started in the 10<sup>th</sup> of July. It was a Friday. I am pretty sure, I want to check that [refer to his journal].”* (P7)

As a reflective step in the coping process, Keefe, Salley & Lefebvre (1992) proposed that journal keeping should be practised. This would allow one to review

coping procedures over time and across domains as well as to review the relationship between specific coping strategies and their outcomes. Such techniques also provide a valuable method for further examining the construct of coping flexibility.

## DISCUSSION

The cognitive-behavioural approaches shared strategic similarities in that participants relieved pain through ignoring and attention diversion, which gave them a sense of control over pain. Participants' awareness of the cognitive influences over pain led them to use these strategies. All participants adopted forms of distraction strategies. Attention-diversion strategies were associated with behavioural strategies of behavioural adjustment and resting during participants' experiential-learning process. Participants developed their own combination of personally favoured distraction strategies.

Behavioural therapy for the management of chronic pain focuses on the cognitive-behavioural components of the patients' chronic pain experience. Cognitive-behavioural therapy (Kerns et al., 1997) highlights the advancement of self-control and self-management through active, organised methods. Patient education, biofeedback, relaxation training, hypnosis, and coping skills instruction are the fundamental elements. The premise of cognitive-behavioural interventions for pain management is to develop and implement coping strategies that will progress the patients' adaptation to chronic pain.

Cognitive-behavioural therapies have been effective in the treatment of lower back pain, headaches, shoulder and arm pain (Basler & Rehfisch, 1990; Kerns et al., 1997; Mason et al., 1998). Cognitive-behavioural therapy highlights the advancement of self-control and self-management through active, organised method (Kerns et al., 1997). Other benefits include the increased use of coping self-statements, patients' disregard of pain sensations, attention diversion, and minimised catastrophic thoughts.

Whatever the course of cognitive-behavioural intervention the key is flexibility and variety when implementing coping strategies along with the developing belief that pain is a controllable stressor (Haythornthwaite et al., 1998). For instance, rheumatoid arthritis patients who were better psychologically adjusted reported using diverse coping strategies within the contexts of daily, work, and leisure activities, as well as in social relations (Blalock et al., 1993; cited in Haythornthwaite et al., 1998). Haythornthwaite et al. (1998) established a positive relationship between explicit coping strategies and

coping flexibility in terms of greater perceived control. Coping self-statements like 'I tell myself to be brave and carry on despite the pain' and reinterpretation of pain sensation were predictive of enhanced perceived self-control and increased self-efficacy. This finding was significant because of its validation of cognitive coping strategies as effective pain management interventions. Further, Arntz et al. (1991) reported that distraction was related to ongoing habituation of experimentally induced pain. These authors suggested that attention-diversion techniques would be a powerful tool for psychological treatment programmes for chronic pain patients.

One universal theme that was consistent with Kelley & Clifford's (1997) findings was participants' use of individualised approaches and coping mechanisms. For some, religion was important; for others, it was meditation, exercises, or entertainment. For some, routine was salient; for others, "going with the flow" worked effectively. Participants reported how they discovered their own coping strategies based on their individual personalities and experiences, some with the benefit of external consultation and information.

## **FAMILY & SOCIAL SUPPORT**

Three codes of family & social support were derived from the data: Seeking Help, Spouse Support, and Support Network. These codes represented support interventions participants reported adopting in response to FMS symptoms, particularly pain. Each of these is discussed below. An overall discussion regarding the changing process of applied coping mechanisms and the association between findings of various coping strategies and existent literature is presented.

### **Seeking Help**

The axial code of seeking help was linked to physical interventions because the process of actively seeking help frequently involved a second party to administer the physical intervention (P1, P3, P6, P7, P8), for instance, massaging (P1) and information seeking (P3). Besides receiving assistance in coping strategies, seeking help from significant individuals also provided participants with physical and psychological support. Seeking help was closely associated with the development of the use of physical interventions and other coping strategies.

*"I have got a hand hold massage from a friend. I have to have somebody hold it." (P1)*

*"First of all mum got some stuff on work. ... My family have been supportive and overprotective sometimes. ... They understand if I am grumpy because I'm tired." (P3)*

*"I couldn't go to bed, I couldn't do anything on my own, without my wife's help. ... Get my wife to pull me out of the lounge chair at night because I can't move." (P7)*

One participant (P4) identified her family members' accommodation of her needs through a prompting system designed to assist her with her impaired short-term memory:

*"a system of prompting for me. We have a wall planner. ... We have a large calendar, where if I am on the phone, I can write on it. ... for urgent things I have to do, we've got a white board. ... I rub them off so they know and I know I have done them." (P4)*

Similarly, P3 expressed her perception of being socially supported when she gained acknowledgement and understanding of her condition from her best friend. This type of supportive behaviour was also offered from school staff during difficult periods.

*"my best friend. She KNOWS everything about it. She talks about it with me. She'll listen and come up with some good advice. Just talking about something helps. ... I am getting extension for things. Some of the teachers've been REALLY REALLY NICE." (P3)*

Two participants' families utilised another form of support, which involved not treating them differently (P2, P5) and/or not acknowledging FMS's existence (P5). This technique would have improved P5's use of cognitive-behavioural strategies such as distraction and avoidance/Intentional denial.

*"They are pretty understanding. They're concerned that they can't do anything, but they don't treat me any differently." (P2)*

*"He (dad) basically ignored it as well. GET ON WITH IT. [treated P5 as] Normal." (P5)*

Some of the other participants discussed feelings of emotional safety and moral support in the presence of significant others. Seeking social support refers to individuals' pursuit of assistance or comfort from significant others such as family, friends, medical-care practitioners, group therapy, religion and seeking information, or other external means.. For example, from family (P3, P4, P6, P7, P8), friends (P3, P8), and/or religion (P1, P3):

*"So basically Bible is the help." (P1)*

*"God, friends and family definitely be my strength through this time. I would probably be somewhere, NOT in very nice place (without any of them). I'd be depressed." (P3)*

*"He's (husband) wonderful. ... Basically I was supported from my husband." (P4)*

Both P3 and P4 felt emotionally supported by family members at home, but also pursued support from peers and groups, which appeared to provide emotional and physical comfort. P4, for example, emphasised the significance of group belonging, which helped in building her self-esteem and managing the symptoms.

*"I have PHASES for couple of days, I'll be quite depressed and then it'll pass. I just talk to friends like my best friend. So, that's good."* (P3)

*"I am very lucky in that I belong to Toast Master. ... It's very self-confidence building. The self-esteem is great. That you are doing a good job and that's helped me."* (P4)

However, at times participants (P4, P6, P7, P8) preferred to cope with their condition on their own, independent of family, friends, and peers. By shielding the effects of their condition from significant others these participants felt better able to manage.

*"I've coped with it my own way. I just plotted alone and I can cope better myself."* (P6)

*"what I've got to do is to manage it myself the best I can with the minimum of help. I tend to believe the only one who can help is me although I worship my wife."* (P7)

Research indicates that social support systems are a particularly important coping resource in terms of general health (Bloomfield et al., 1992). There is now considerable evidence that social factors play a role in pain experience and can influence both the perception of sensory intensity and the resulting pain behaviour (Koutantji et al., 1998). Chronic pain can reduce social and psychological functioning, although social support can benefit through social work intervention. However the quality of the social support system is determined by the extent to which individuals believe family and friends care, how much they trust and confide in family and friends, and whether they can access them in times of need (Miller, 1993).

### **Spouse Support**

Three married participants (P4, P6, P7) reported receiving substantial emotional support and ergonomic assistance from their partners since the onset of their condition. To reciprocate support from his spouse and in recognition of her own difficulties, P7 was open to discussion on her concerns. P8 continued to value her husband's support even though they were experiencing marital difficulties because of his lack of understanding of her condition and the lack of success of counselling sessions.

*"Emotionally I am happy and I've got a wonderful husband. ... Our emotional relationship is still fine. I am very lucky with that."* (P4)

*"I couldn't go to bed, I couldn't do anything on my own, without my wife's help. ... Get my wife to pull me out of the lounge chair at night because I can't move. ... She KNOWS there's something physically wrong with me and accepts it. ... my way of helping her is taking on her, let her talk to me." (P7)*

*"My husband's put up a lot for me. ... He dreaded the day when he signed the paper when I got committed on section 21. He thought it might be the only way for ME. ... We've had arguments but he stuck with me and he's still with me. I've got to think must be something there, but I've still got this wall around me." (P8)*

The present data is consistent with existent literature that spouse support is crucial in reducing chronic pain patients' depression severity. Social support offers assistance in preventing patients' stress by reducing the importance of destructive and intimidating events. Literature reviews reveal a pattern of well-adapted chronically ill patients coming from cohesive, creative, supportive, and flexible families when adjusting to changes of life (Jamison & Virts, 1990). Further, perceived social and family support has being linked to arthritis patients' quality of life and functioning, inversely associated with chronic pain patients' perceived pain intensity and depression, and predictive of positive treatment consequence. Data from this study also supports the significance of spouse support in FMS sufferers' physical state and mobility. Along with other research findings, Jamison & Virts (1990) concluded that insufficient social support may contribute to poor health outcomes.

## **Support Network**

P6 and her mother described the significance of accessible support:

*"Umm [live by her daughter]. Yeah, just about everyday [to visit P6]. ... We'd go and get our groceries and go shopping together. Umm (P6 & her mum) [help P6 out]."*  
(P6's mum)

One participant (P4) had been involved in group support, although it was intended for suffers with general chronic pain and was often inappropriate. Two participants (P1, P8) had been actively seeking membership of a peer support group for FMS, but had been disappointed (as previously discussed in social support intervening condition, in chapter 10). Other participants (P2, P3, P5, P6, P7) mentioned the desire to join a support group if one was available for FMS.

*"I just nominated down a management programme up at the hospital.... It would be really great to have to be involved with a specific one. This one is more generalised. I have a feeling this lady in Wanganui that's trying to set up a fibromyalgia support group and I've got to try and contact her. I would be happy to join a group like that. This strength in numbers and one of us might find out something and another one finds out something else and we can then pool ideas together."* (P4)

*"If there was a support group that I was aware of and I'd go. But at this stage I am not in it. No support group at the moment."* (P3)

*"Yeah, if I wasn't coping, maybe it [support group] would be good. But I feel I CAN cope, but I don't mind people coming to me and talking about it if they want to."* (P6)

Jamison & Virts (1990) discovered an additional concept in relation to the significance of social network type. Patients who have access to a bigger support network, for example, who live nearby extended family members and come from larger families, and whose personalities are likely to cultivate support tend to manage chronic pain more adaptively. This has implications in today's society where households tend to move more frequently and tend not to live near extended family members.

Similar to chronic pain patients' reports of Jamison & Virts' study (1990), participants believed they benefited from having access to a bigger support network, living nearby extended family members, and/or possessing personalities that were able to cultivate social support.

Participants in this study who received group support reported such cognitive-behavioural strategy to be efficacious as proposed by Turk et al. (1983). They gathered a sense of group belonging and acceptance through sharing their similar experiences, difficulties, and knowledge, particularly when considering the FMS condition to be an invisible illness and have received minimal social understanding.

However, several participants described the lack of sufficient social network for FMS patients and the consequences of this, such as limited knowledge and access to support and infrequent group meetings as previously mentioned in relation to social support as an intervening condition (Chapter Seven).

Overall, literature has underlined the impact of perceived social support on the successful management of chronic pain. Appraisal of an individual's social and family support, mobilising his/her social network and family members' involvement in the treatment programme all advance chronic pain patients' rehabilitation.

## DISCUSSION

Numerous studies have centred on the negative role family can play, especially the spouse, in maintaining chronic pain behaviour. Research indicates that family's supportive reactions sometimes reinforce the patient's pain behaviours (ie. such as frowning, moaning, bracing, rubbing, and guarding) (Gil et al., 1987). Patients commonly use these behaviours to communicate their suffering and the spouse can become a cue for these behaviours, which suggests that excessively supportive families can frustrate chronic pain patients' adaptive coping.

Social support has been identified to be critical for reducing stressful consequences from pain (Gatson-Johansson et al., 1990). In this study, all participants described the importance of feeling supported by their significant others throughout the course of FMS experience, particularly during severe pain episodes.

Family and friends were the most frequently discussed social supports, as well as the immediate extended sufferers of the illness condition, which correlates with Miller's (1993) proposition. They perceived familial nurturance, support, and involvement to be of major importance. Married participants identified spouse support to be vital, particularly during painful, physically immobile, and/or depressive episodes.

Consistent with present findings, Jamison & Virts (1990) and Koutantji et al. (1998) reported that social and family interactions was predictive and a crucial construct for their physical and psychological conditions. Participants typically valued the significance of family members' supportiveness, cohesiveness, and flexibility to accommodate their condition. This was in contrast to Gil et al.'s (1987) suggestion that a supportive family could be detrimental to chronic pain patients by interfering with adaptive coping, particularly if exhibiting pain behaviour was reinforced.

Turk et al. (1983) noted that group approach as a form of cognitive-behaviour pain management proved efficacious by promoting self-disclosure, cohesiveness, pressure, and public commitment. One example is the support group in which peers with similar conditions meet for mutual support (Gildenberg & DeVaul, 1985). The 'treatment' revolves around group discussions between patients with similar problems, with or without a therapist. Benefits include social support, education, and a means of re-entry into responsible social interaction. The opportunity for support from those with similar problems but at various stages of rehabilitation is evident. Peers accept and encourage each other. They also confront fellow patients who relapse into familiar pain

episodes. Participants reported their improvement was partially due to the sense of group belonging through the sharing of similar problems (Turk et al., 1983).

## PERCEPTIONS OF EMOTIONAL STATE

This selective code consisted of participants' descriptions of how they perceived their emotional state. Perception of emotional state refers to the intervening influence of individual awareness of their own conditions and how this awareness was shaped by conscious arousal and feelings brought on by experiencing their conditions. Perceptions of emotional state are critical in their effect on individual propensity to act in response to the FMS symptoms with appropriate coping strategies. Specifically, a close association between the perceptions of emotional state and the use of coping strategies emerged from the data. The perceptions of emotional states were coded intentional denial & apprehension, frustration, feelings of control, and acceptance and their experience appeared critical if coping strategies were to be used effectively. The perceptions of emotional state emerged as both a condition for the use of coping strategies and a consequence of the participants' selected coping strategies. Subsequent analysis confirmed the necessity of including the perceptions of emotional state as an integral part of the process of becoming accustomed to pain. Participants' perceptions of coping outcomes contributed to these feeling states and some perceptions of coping effectiveness overlapped with those mentioned previously. Each of the four emotional states is discussed below in the order in which they are most prominent in relation to the time since the onset of participants' FMS conditions.

### Intentional Denial & Apprehension

Intentional denial and apprehension typically characterised participants' emotional response at the early stage of their illness. Participants exhibited these types of feelings in relation to the acute onset of severe symptoms and pain, when they did not understand their condition or the causes. A close relationship was established between Intentional denial or apprehension, insufficient knowledge of the FMS condition, and recurrent severe symptoms and pain.

*"Yes, I do deny it, I am SO afraid of people knowing that I am SICK. There is this horrible, overwhelming feeling inside when I say to somebody 'I'm sick'. (P1).*

*"At first I was a bit concerned I was being told I had this thing that sounded terrible. ... I was PRETTY UPSET when I first heard that I didn't know what it was." (P5)*

### **Frustration**

Participants (P2, P3, P4, P5, P6, P7) frequently expressed feelings of frustration and/or annoyance with constant pain, although such feelings were integrated into their acceptance and increased tolerance for pain at later stages of illness (refer p. 124-5 for acceptance). Feelings of frustration varied individually and were not always explicit in the transcript. For example, P7's statements could be interpreted as an expression of frustration and injustice from being inflicted with FMS.

*"Probably just the frustration, not being able to do things that I used to do." (P2)*

*"You look at a metaphorical mirror and 'what have I done to deserve all this'? I look at the bad side of the scale, well, I am not a child molester, I am not a rapist, not a murderer, never burgled anyone, never killed anyone in a car. And I look at the good side, but there's nothing on the good side! You ask yourself 'why, why bother!'" (P7)*

P5, whose FMS condition had improved, felt *"annoyed"* with the continuously recurrent and severe pain through her adolescence. This was because during all this time she was restricted from participating in any recreational and social activities like her peers. These feelings are not surprising considering the importance of peer groups and group belonging during adolescence.

*"any kind. I used to do gymnastics, tennis, squash, netball, soccer, used to love tramping ... growing up as a teenager, I couldn't do something I WANTED to do." (P5)*

The limits imposed on activity caused frustration in participants also. This frustration appeared to result from being unable to conduct, or having to discontinue or adjust a favoured activity. For instance, P6 felt a sense of frustration because *"you can't do what you want to do"* and depression because *"when you realise there's a lot of thing you can't do, you start getting SICK of it"*.

*"That's the WORST part of it. It does make you depressed. Because it's frustrating. I get SHITTY because I can't do what I want to do, more than anything!" (P6)*

P4's sources of frustration amounted to *"feeling useless"* and an attitude of *"why bother"* because she was unable to help her family with housework and parental duties during the early stage of FMS. As a result, she felt excluded from the 'mother role'.

*"A REAL sense of frustration because of my injury Tony and Kasya were taking on the mother role. Now I am more physically able, I have to fight to get it back."* (P4)

Five participants (P3, P4, P5, P6, P7) experienced conflicting feelings over the need to limit activities and their desire to act.

*"I love swimming. That's a two-edge sword between when I get cold I shiver therefore the muscles tense up and the benefits."* (P4)

*"I spend AWFUL a lot of time in my museum. I've known for months I can't do that anymore. ... Learning to say 'enough is enough' and being able to do NOTHING. ... I can no longer drive a manual car and I've got rid of them, because I walk outside I end up crying because I KNOW I'd never be able to drive them. NEVER."* (P7)

Furthermore, a sense of 'differentness' from the norm was evident throughout transcripts and appeared to influence participants' decisions about pain expression and when to withdraw from a group activity. This was a particular concern for the youngest participant who was in her adolescence and showed desire for affiliation with her peer group. P3 expressed her feelings of 'differentness' in comparison to her peers in social contexts. She was quite concerned with looking normal. For instance, while attending the theatre, P3 would reject her mother's request to use a cushion and also attempted to limit her movement (long periods of being stationary are uncomfortable) so as to appear normal. Like P3, P5 expressed her frustration – *"used to drive me up the wall"* – as a result of inability to participate in groups and her feelings of 'differentness'.

*"I try not to be that different. ... it looks WEIRD. In public places."* (P3)

*"... when I was growing up as a teenager. All my friends were going out because quite often I'd have an injury of some sort and couldn't go. So in that regards, my joints limited me and that was when your parents, of course, want to do the best for you and say 'no, you're staying home' and then they just used to drive me up the walls."* (P5)

In addition, not wanting to be different and a sense of group belonging prompted P3 into continuing with social activity even though this caused more severe and prolonged pain.

*"I pushed myself too far going to this ball. I was in quite a SUBSTANTIAL amount of pain afterwards. I was just feeling REALLY, REALLY horrible."* (P3)

In summary, participants simultaneously experienced feelings of frustration. The most common sources of frustration were physical limitations, with feelings of being different from others, and social misperceptions as less frustrating (see Chapter Seven for social support intervening conditions).

## Feelings of Control

Participants' ability to manage pain and control other FMS symptoms through the adoption of effective coping strategies confirmed perceptions that they had improved since onset. While insufficient control of symptoms, uncontrollable pain, unknown outcomes, and fear characterised the early stages of FMS, feelings of being knowledgeable and in control of FMS characterised the later stages. P7's realistic perceptions of the limitations of the amount of control he had over pain were balanced against feelings of being in control.

*"It WAS [FMS was important], but I don't think it is NOW because it exists. I can't take it away so I am not going to make my FMS FEEL GOOD by talking to it all the time and telling how bad it was and knows it's there and reminds me. ... I am bloody sure I can't change it, so why give it any more importance than it actually is." (P7)*

One participant (P5) expressed having had control over pain with the exception of her knee. This is similar to P7's earlier remarks of being able to handle all other symptoms except tinnitus:

*"And as for my knee, I just gave up." (P5)*

The unpredictability, severity, and uncontrollability of pain decreased P5's perceptions of being in control. To allow herself to live a near normal life, P5 chose not to let pain take control over her by ignoring it as much as possible (refer Chapter Eight for coping strategies).

*"I stopped worrying about it, I wouldn't allow myself and that sort of worked." (P5)*

Participants' feelings of control were outcomes of their use of numerous coping strategies (discussed in Chapter Nine), including the use of a non-defeatist attitude; positive attitude; behavioural adjustment; frequent movement; stopping and resting; and self-management of physical interventions. All interviews indicated that participants subsequently regained and maintained some form of control of previous pain experience through cognitive resolution, increasing awareness, habituation of their symptoms and pain, and the use seemingly effective coping strategies they had learned.

Participants were able to recognise the limitations of their control over pain. Commonly, this stemmed from the severity and unpredictability of the condition and pain, which could not be attributed to antecedent events.

Paradoxically, participants also found “letting go” useful, since they learned they had to accept things they could not control. Participants described feelings of being able to control pain alongside an awareness of the limitation to the amount of control they had over the pain.

Participants identified accurate information during the early stages of their condition as particularly important for their development of feeling in control after their FMS diagnoses and initial treatment intervention, as previously discussed in behavioural coping strategies.

These findings are consistent with Folkman’s (1984) conceptualisation that appraisals of control can change as a stressful encounter unfolds. The overlap between appraisal and use of coping strategies, and how they interact with each other, described by Folkman (1984) was evident in the present descriptive data and conceptual analysis. For example, participants described how they became less concerned with the pain because they had found ways of managing it, so then it seemed less sore. Participants’ experiential learning of coping strategies that relieved pain and increased self-efficacy beliefs influenced their subsequent appraisals and use of coping strategies. Subjective habituation to pain (tolerance for pain) also directed both appraisal and use of coping strategies.

Overall, participants’ increasing tolerance for pain, increased self-efficacy, and increased feelings of control over pain were closely associated with one another.

## Acceptance

Although concerned with his physical debilitation, P7 has developed a philosophy of being a “*pretty adaptable human being*”, which helped him to approach ageing and the continuation of his condition and pain with a more positive, accepting attitude, despite his tinnitus.

*“I don’t worry about it. Whatever happens happened. I am 50 years old. I can HANDLE aches and pains, not being able to get out of bed occasionally.” (P7)*

Most participants (P1, P3, P4, P6, P7, P8) openly admit to having their illness, although some did struggle initially with their illness perception.

*“Yeah. Now I can, now I have to. There is no room for negotiation.” (P1)*

*“Yeah! I mean I struggle with that for a while ‘am I INJURED or am I SICK’? IT was kind of a decision, DEFINITELY SICK NOW!” (P3)*

Participants' acceptance of their conditions and pain appeared to contribute to increasing tolerance for pain and the escalating sense of control engendered by the effective use of coping strategies. All participants (P1, P2, P3, P4, P6, P7, P8) claimed that living with pain was part of their lives. Moreover, their tolerance for pain had increased while attempting to live a normal life.

*"I am admitting to people I am sick now. There is no room for negotiation."* (P1)

*"It becomes natural. You can't SEPARATE yourself from physical PAIN and everything. I've got used to it, accept the pain's there all the time and live with it."* (P3)

*"The pain threshold's gone RIGHT DOWN, but the tolerance of it has gone UP."* (P7)

*"I've taken more pain than I would normally. I am accepting more pain thinking 'it's there, so what, get on with it'!"* (P8)

The intermittent and changeable nature of FMS pain and symptoms moderated the degree of daily acceptance, which determined that day's activities and activity level (refer Chapter Six for The phenomena).

Acceptance of the pain allowed participants to more effectively monitor their experience and cope accordingly.

*"I am much more aware of what's happening within my body. I can tell the difference between different pains and different headaches. I am more finely tuned."* (P4)

All participants reported accepting their condition and pain, which allowed them to adjust better with their modified lifestyles. Acceptance was related to both the use of cognitive strategies that altered the appraisal of pain and was a consequence of those strategies. This is in accord with the findings of Holmes & Stevenson (1990) and McCracken (1998) regarding positive adaptive outcomes in chronic pain patients.

Acceptance was associated with less distress and less need for information. This is consistent with the findings of Turner et al. (1987). Although acceptance was associated with less distress, frustration could still exist alongside acceptance. For instance, feelings of being different from their peers still produced frustration even though participants accepted their condition. The participants' data also indicated that acceptance was associated with participating in as near normal activities as possible, as well as using cognitive strategies that addressed the pain. This was similar to Turner et al.'s (1987) description of chronic low-back pain patients who believed that they do not have to hold back and utilise problem-focused coping in association with acceptance.

In summary, acceptance was closely related to the outcome of participants' perceptions of knowing how to relieve pain effectively and their belief that pain could be

managed. Increased tolerance for pain, or alternatively, becoming accustomed to pain, also contributed and resulted from acceptance.

## DISCUSSION

The use of coping strategies was situation-specific and participants re-visited the stages of the process with individual variations, depending on contextual variables. Specifically, the inductively generated theory and its constituent data – subjective habituation, experiential-learning, and lifestyle adjustments – described how the process of living with chronic pain both informed and was a consequence of the use of coping strategies.

The changing process of living with chronic pain that was generated from the participants' data, is consistent with Suls & Fletcher's (1985) concept that the use of coping strategies changes over time. It also supports Horn & Munafo's (1997) individual and situation specific theory, that coping behaviour is influenced by individuals' personal and situation resources. Changes in the use of coping strategies interacted with changes in appraisals and contexts and the perceived consequences, through which participants felt that pain was controllable and which all facilitated participants' progressions throughout stages of their FMS experience.

Folkman's (1984) findings on participants' situational appraisals leading to a belief that they could initiate strategies capable of controlling pain parallel Bandura's (1977) concept of efficacy expectancy. Specifically, an increased efficacy expectancy was described by participants as they became increasingly adept at using coping strategies they had developed to relieve pain. In Bandura's (1977) terms, "*personal mastery experiences*", raised the participants' beliefs that they are able to initiate coping strategies that will relieve pain. This is referred to as "increased perceived self-efficacy" in the present report.

Through the use of cognitive strategies, the significance of pain in the patients' lives was reduced. In a way, these cognitive strategies collectively represented a type of *perceptual adaptation* to the sensation of chronic pain. Perceptual adaptation refers to a perceptual mechanism whereby an individual's senses adapt (desensitise) to the presence of a continuously present stimulus. For instance, when exposed to the same smell over a prolonged period of time you begin not to notice it or, rather, your senses attenuate to the stimulus.

Consistent with Keefe et al.' (1997) results that self-statements, ignoring pain sensations, and reinterpreting pain sensations were predictive of rheumatic arthritis patients' self-efficacy beliefs, additional coping strategies were found to share the same predictive mechanism in the present study. That is, cognitive resolution of antecedent events, behavioural adjustments, physical interventions, and distractions were associated with perceived self-efficacy. Participants' feelings that they could control pain arose from previous effective use of coping strategies (and realising what strategies were less effective) and gain increased knowledge about potential antecedent exacerbating cues. Contrarily, beliefs that pain was uncontrollable and exceeded the level of tolerance would induce anxiety, as specified by Thompson (1981). For instance, several participants identified anxiety attacks when pain and other FMS symptoms were beyond their manageable limit.

Supportive of Haythornthwaite et al.'s (1998) conceptualisation, FMS participants' flexibility in implementing diverse coping strategies and their belief in pain being a controllable stressor were significant predictors of their adaptation to their conditions. Specifically, a non-defeatist attitude was adopted and a disregard of the pain sensations made up the most commonly used cognitive strategies. Success with these strategies was associated with perceived control and increased self-efficacy.

The severity of FMS symptoms (pain in particular) in conjunction with other contexts (such as situational context and the length of time since onset) was predictive of the use of a range of coping strategies. Affleck et al. (1992) also found complex relationships between severity of pain, use of coping strategies, and positive mood in rheumatoid arthritis patients. Severity of pain served as a moderating variable with the use of specific coping strategies and outcomes. No specific correlational relationships were extrapolated from the present study. However, the emergent theory developed from the participants' data indicated the severity of pain as a moderating variable, both in participants' judgements of the effectiveness of coping strategies and their use of coping strategies.

Turner, Clancy, & Vitaliano (1987) noted the importance of viewing coping with chronic pain as a process, with different coping strategies used at different phases, although the detail of such a process has not yet been described. These authors found that adults who had not experienced pain before were more likely to seek social support, and suggested that seeking social support may be most useful in the early stages of coping with a pain problem, when uncertainty and anxiety were likely to be higher.

As proposed by Silver & Wortman (1980, cited in Holmes & Stevenson, 1990), no one coping strategy is superior to the others. Each coping strategy generated positive outcomes under different circumstances as long as they were adequately used. Surprisingly though, some patients continue with strategies despite evidence that their efforts have no effect. Horn & Munafo (1997) termed this as “immature” or “unrealistic” coping. Patients judging a stressful situation as permanent can further worsen their psychological distress (Vitiliano, DeWolfe, Maiuro, Russo, & Katon, 1990). The theory, inductively analysed from the participants’ data in this study, illustrated a similar process in the change in use of coping strategies across time as was found by Holmes & Stevenson (1990) and Suls & Fletcher (1985). Both Holmes & Stevenson (1990) and Suls & Fletcher’s (1985) studies indicated that recent-onset chronic pain patients were more positively adapted in the short-run when they employed primarily avoidance coping strategies, because these strategies provided immediate relief from stressors. Participants were more positively adapted when they employed primarily attentional (or problem-focused) coping strategies like reappraisal or information seeking, which provided superior long-term effects. However, contrary to the preliminary findings, information seeking occurred alongside avoidance strategies relatively soon after onset in some cases.

# CHAPTER NINE

## The Consequences

This chapter investigates the axial codes and categories from the data for inclusion in the paradigm model as ‘consequences’. There are six general sections related to consequences: illness impact on health & related matters, illness impact on emotions, illness impact on social relations, illness impact on employment, illness impact on relations with health care services, and general impact of living with chronic pain. Although each of these sections is attended to individually in the following report, there is considerable interrelation among them.

ILLNESS IMPACT ON HEALTH & RELATED MATTERS	
General Impact on Health & on the Body	Physical condition
	Symptoms developed since onset
Cyclical Effects	Pain-sleep-fatigue-pain cycle
	Cognitive effects of the cycle
	Impaired daily functioning
	Reactions to impaired daily functioning
ILLNESS IMPACT ON EMOTIONS	
Feelings about Self	Control, independence, & vulnerability
	Emotional effects of pain
Feelings about the Illness	Worry & pessimism
	Emotional distress
ILLNESS IMPACT ON SOCIAL RELATIONS	
Social Effects on Participants	A decline of social activity threshold
	Social avoidance
	Social morbidity
	Social isolation
Social Effects on Significant Others	Impaired functioning as parents
	Impaired family functioning
	Impaired intimate relationships

ILLNESS IMPACT ON EMPLOYMENT	
Effects on Career & Employment Opportunity	Unemployment & job maintenance
	The FMS employees: Type A personality
	Shifts in future occupations
Financial Effects	Financial restrictions from inability to work
	Financial restrictions from constant medical charges
ILLNESS IMPACT ON RELATIONS WITH THE HEALTH-CARE SERVICES	
Satisfaction with Medical Practitioners	
Satisfaction with Diagnosis	
Satisfaction with Medication & Treatment	
Satisfaction with Accident Compensation Commission Services	
GENERAL IMPACT ON LIVING WITH CHRONIC PAIN	
Overall Perceptions of FMS Experience	
Effects on QOL	

Table 3. A classification of the overall impact of FMS on sufferers

ILLNESS IMPACT ON HEALTH & RELATED MATTERS

Two categories of illness impact on health & related matters were derived from the data: general impact on health & on the body and cyclical effects, which are discussed separately below.

General Impact on Health & on the Body

Two sub-categories of general impact on health & on the body originated from the data: physical condition and symptoms developed since onset, which are discussed below.

Physical condition

Participants’ condition varied since the onset of their FMS conditions. Most participants described a gradual deterioration in their physical health since the onset(s), particularly once they were diagnosed with FMS. P1 stated a general decline in her health, while P4 mentioned the emergence of new symptoms; and P3 and P7 commented on the salience of muscular pain.

*"My body IS broken. ... My health has gone absolutely bananas." (P1)*

*"My muscles are just COMPLETELY WEAK, my back ones are the worst because my back injury. ... I am still getting worse at this stage." (P3)*

*"showing FMS was worsening is the muscles in my chest are coming in." (P4)*

Both P4 and P6 described an increased sensitivity to climatic variation as a form of physical weakening.

*"I am more sensitive to cold than I used to be." (P4)*

*"Joints and muscles tell a couple of days before rain and if it's cold I get very sore, if it's too hot I get sore." (P6)*

Further, these two participants (P4, P6) reported fluctuation of their physical status in a cyclic fashion. For instance, P4 describes a plateau in the severity of pain. P4's pain severity fluctuated at or below this plateau of pain on a frequent basis. The dampness of the atmosphere during the previous winter was additional pain catalyst for increased pain for P6 after years of successful management.

*"I am not getting worse ALL the time. I am worse some days and better others. There is plateau, I come down, plateau, and the plateau could be a long time. ... I have periods when it's worse. And period when it's better and so on. ... It's more of a cyclic thing." (P4)*

*"It HAS GOT BETTER, but it has been back once or twice, where it's been really sore. ... It's SO damp." (P6)*

Two participants' (P5, P6) reported improvement in their conditions through their use of individual self management strategies. P5 used ignoring and P6 self-monitoring. P5 reported reduced frequency of symptoms and reduced severity of pain, while P6 emphasised that the reduced stress in her life assisted the improvement of her FMS condition.

*"if neck goes out, it's very painful. It's only every two months (now). Otherwise it's just a bit DIScomfort than severe pain in my shoulder. Weekly or fortnightly." (P5)*

*"started to improve. ... I am now out of my stress side because my children are now left home and I am not under any stress so it's made a big difference." (P6)*

The description of impact for some participants to support Henriksson's (1994) report that pain was diffuse and widespread in FMS. Participants also reported the deterioration of their FMS condition and increasing pain, which is contrary to non-degenerative, non-progressive nature proposed by Starlanyl & Copeland (1996).

Evidence from this study appears to support Masi & Yunus' (1986) three potential courses for FMS with most participants reported having experienced a *progressive* course of FMS in general although some did experience the *fluctuating-continuing* course and one participant reported being at the *remitting-intermittent* stage of their FMS conditions.

### Symptoms Developed Since Onset

Two codes of Symptoms Developed Since Onset were derived from the data: idiosyncratic symptoms and weight fluctuation. The physical consequences of sleep disruption, lowered endurance, and fatigue were **idiosyncratic symptoms**, which varied in individual cases. Other idiosyncratic symptoms that developed consisted of impaired co-ordination (P2, P3, P4, P6), chest pain (P4, P6), P7's tinnitus, hair loss, dizziness, vertigo, grinding teeth (as a form of stress).

*"A lack of co-ordination. I'm dropping things or reach something and I miss it." (P4)*

*"It's all side effects. ... dropping things, chest pain. I think I was having a heart attack but it was bloody muscles in my chest. I couldn't breathe." (P6)*

*"Ringing in the ears started and that blew me away. ... I read a book the word will disappear or it get really big or leap up the page at me. ... since the operation, I've gone what 90% bold. ... the dizzy bit, falling down ... loose my balance. ... a recent phenomenon. ... same time as the ear started, the GRINDING of the TEETH started AT NIGHT, OCCASIONALLY during the day, ONLY when I am not concentrating." (P7)*

P7's newly acquired symptoms – dizziness and vertigo – are supported by Ediger's (1991) dysequilibrium of FMS symptom. FMS patients may experience dizziness and balance problems, which may be the result of an affected vestibular system (Ediger, 1991) Typically, there is no classical, spinning vertigo. Rather, difficulties in orientation occur when standing, driving, or reading.

Most participants reported **weight change**, with some reporting weight loss (P1, P3) and others weight gain (P2, P4, P7, P8), due to altered eating habits for various reasons. For instance, loss of appetite due to pain intensity (P3, P4), "*pigging out*" as a form of 'releasing' from pain and sleep deprivation (P2), lack of physical movement (P4, P7), or medication side effects (P8). P4 experienced loss of appetite due to physical discomfort, although she consequently gained weight because of insufficient physical exertion imposed through limited daily activities.

*"haven't eaten as well, lost weight, DON'T WANT to eat, pain and everything," (P3)*

*"I pigged a lot of the time. Even though I might think it does [relieve pain], it doesn't. ...*

*Sleep deprivation hasn't reduced things. Probably I want to eat more." (P2)*

*"have put on a lot of weight since I've been off work. Because the inability to exercise. ...*

*I'm eating a lot less. I'm not hungry and physically I feel uncomfortable a lot." (P4)*

*"My weight has been going up and down like a yo-yo. Some of it's been antidepressants*

*I've been on. I've piled on weight." (P8)*

## **Cyclical Effects**

Four sub-categories of cyclical effects were derived from the data: pain-sleep-fatigue-pain cycle, cognitive effects of the cycle, impaired daily functioning effects of the cycle, and reactions to the impaired daily functioning effects of the cycle. Each of these is discussed below independently, but once again there are considerable interrelations among them.

### **Pain-Sleep-Fatigue-Pain Cycle**

Most participants had disrupted sleep (P2, P3, P4, P7) since the start of their FMS condition. Lowered energy levels (P2, P6, P7) in the morning were a common side effect of sleep disruption, as were feelings of tiredness (P2, P3) and sleep deprivation (P3, P8).

*"sleep disturbance. Insomnia. I now struggle to get up in the morning. Because I just feel stiff, I just feel like I am still tired." (P2)*

*"I wake up through the night. ... wake up so TIRED it's like I might as well STAY UP THE WHOLE NIGHT. There is no point in me going to sleep." (P3)*

Participants reported a need to adjust their lifestyle because of the physical consequences of FMS. Three participants (P1, P3, P8) thought that their diminished energy reserve impacted on their quality of life. Both P1 and P3 thought cognitive impairment to be both the consequence and contributor to daily routine changes.

*"HAS affected my life significantly. Going to bed this early is REALLY SHOCKING. Physical tasks are harder and I am TOO TIRED to do what I used to do. Like doing homework after school, I am SO TIRED so my mind is just NOT AWAKE enough." (P3)*

Closely associated with fatigue is a decreased tolerance for exercise. This has been defined as *"the perception of muscular fatigue and great muscular effort after only a few dynamic muscle contractions or after static work of short duration"* (Henriksson & Bengtsson, 1990, p. 673). Although not recognised in the ACR criteria, exercise

intolerance, was later specified in the Copenhagen Declaration (Henriksson & Bengtsson, 1990).

The literature indicates FMS patients perceive fatigue as far more debilitating than undue pain, which inhibits them from fulfilling daily tasks (Henricksson et al., 1992). Limitations in physical functioning, impaired physical fitness, and prolonged time taken to achieve tasks were reported as recurrent stressors by FMS patients in Henriksson's qualitative study (1995, cited in Affleck et al., 1998).

Chronic pain, continuous fatigue, and sleep disturbance are threats to one's quality of life (QOL). QOL is defined as people's "*perceptions of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns*" (WHOQOL Group, 1993, cited in Skevington, 1998). One's daily emotional wellbeing can be predicted by the severity of chronic pain (Affleck, Tennen, Urrows, & Higgins, 1992), fatigue (Stone et al., 1994), and quality of sleep (Totterdell et al., 1994).

Continuous pain leads to sleep disturbance and fatigue for FMS sufferers, which can have a wide range of effects. FMS patients suffer higher frequency of depression and reduced social functioning compared to both the general population and other chronic pain sufferers (Gaston-Johansson et al., 1990). Many of them suffer enormously from somatic and psychological distress (Uveges et al., 1990). For instance, FMS can impair physical functioning and mobility in most patients (Henriksson, 1994; Neumann & Buskila, 1997), resulting in reduced quality of life (QOL) (Henriksson, et al., 1992; Burckhardt, Clark, & Bennett, 1993), deteriorating health status, and dissatisfaction (with, for example, work, environment, economic resources, relationships, and leisure time) in a cyclical way.

Consistent with previous research findings (Affleck et al., 1992; Stone et al., 1994; Totterdell et al., 1994), data from the present study indicates that chronic pain, fatigue, and sleep disturbance were the major health threats to and predictive of participants' quality of life (QOL). Chronic pain and discomfort particularly were the primary stressors to affect participants' QOL and physical and emotional wellbeing as proposed by Skevington (1998).

### **Cognitive Effects of the Cycle**

Most participants reported being affected cognitively from a physical cycle, typically pain → sleep disturbance → fatigue cycle reported above. A decline in concentration was experienced by P2, P3, P4, P6, and P8, as were losses in short-term memory effectiveness were reported by P4, P6, and P7, and general cognitive impairment by P1. P4 was emotional distressed at her impaired short-term memory.

*"It does at times. Probably because I am tired a lot. Because I don't get a good night sleep and then you have to cope with the pain and stuff."* (P2)

*"if you don't give me the right prompt, I don't remember. At night is worst, they ask me to do something and I agree. But, in the morning, it's as if that situation didn't existed, I have no memory of it until someone reminds me. ... I forget. It's so frustrating."* (P4)

*"I've got short-term memory loss. It DOES happen to me everyday. I go to the kitchen, I go to the garage, 'what the hell I am here for'?"* (P7)

*"When I am down, I have no BRAIN POWER."* (P1)

Participants' (P3, P6, P7) satisfaction with accomplishing tasks has decreased due to both their physical inability and cognitive impairment as a result of a lowered energy reserve. Both P3 and P6 claimed they have habituated to such impairment as a way of coping.

*"I had a slight disappointment when the marks were low. But I have to be realistic and think 'you are not going to get the marks you were getting beforehand'. I don't have the ENERGY to do the work."* (P3)

### **Impaired Daily Functioning**

Some participants mentioned driving difficulties as a result of impaired co-ordination (P2), muscle weakness (P2), a lowered concentration span (P4) and general physical weakness (P1, P5).

*"foot on accelerator quite uncomfortable, leg very weak. ... sciatica at one stage."* (P2)

*"bad day, changing gears is a problem. Partly because of inability to concentrate."* (P4)

*"The car I drove before was old and that was HARD work, it took a lot to drive."* (P5)

Three participants (P2, P5, P6) further reported experiencing difficulties with long-distance driving because of musculoskeletal and articular surface problems including numbness (P2), soreness (P5, P6), and stiffness (P6).

*"When I am long distance driving, my foot goes completely numb."* (P2)

*"I have a job lifting my legs to get into the car because my back's so sore. ... I get too stiff and sore and I've got to get out and have a stretch."* (P6)

All participants reported limited physical exertion as a result of their FMS conditions, particularly pain:

*"It restricts your exercise ... because of PAIN"* (P1)

*"For physical activities, like sports I can't. I used to do cross-stitch but that's quite, causes pain again too. Yeah [more indoor person now]. Not that I was overly sporty, I was trying to find exercises that'd be helpful. ... I can't do gardening. It's probably just the hand work really. But writing, I haven't been able to do a long length of time because then my wrist just gets really tight and sore."* (P2)

*"I've gone from being able to play fight with my husband to not anymore. Because the fact that if he hit me, he knocks me or anything like that, it's so painful. ... Because of the back injury, things with where I have to bend and maintain that posture are very difficult. Things like doing dishes, ironing, vacuuming, sweeping, cleaning, those sorts of things are very difficult. Making beds. ... Anything where I have to maintain a position for any length of time is a problem. ... Walking causes all sorts of problems because of fibromyalgia. They talk about the chest pains like constraint, muscle spasms in your chest and back. I get that when I try walking. Not under normal circumstances, but if I try any walking distance that happens and it's very very painful. ... I've tried biking and biking is too painful. ... I love swimming. That's a two-edge sword between when I get cold I shiver therefore the muscles tense up and the benefits."* (P4)

*"I can DO them, but they take a lot LONGER to do. I suppose I am limited, but no, I still do them somehow! Well, you find different ways of doing things. might take a lot longer, just depends on how you're feeling at the time. ... Umm [that would limit self wanting to go out]. I am quite happy to stay at home, as long as I don't have to get my pain."* (P6)

In terms of motor functioning, most participants in this study reported experiencing difficulties in performing activities, especially activities requiring strength and endurance. Henriksson et al. (1992) concluded that a poor handgrip, stiffness, clumsiness, and dropping objects could be due to muscular weakness or poor motor control. Henriksson (1994) and Neumann & Buskila's (1997) research findings support the observation that motor function is affected. Several participants in this study reported that frequent micro breaks during activities involving static muscle work allowed them to continue the activity over a longer period. However, these short rests increase the amount of time needed to perform a task.

### Reactions to Impaired Daily Functioning

Over time, these participants suffered a gradual physical deconditioning, so that even the most mundane daily tasks presented major hurdles. Participants referred to a continual lack of energy as a major inhibitory factor against executing daily activities. For instance, cooking preparation (P1, P4) became such a problem that many participants had to modify their diets in order to accommodate the limitations imposed by their conditions.

*"The food now I am preparing for the family is quick and easy." (P4)*

Two participants reported to have readjusted (P1) and/or limited (P1, P4) physical activities as a way to cope with daily life changes, while P2 had to modify her living arrangement by choosing to live on her own.

*"Going to the pools, the park, the science centre or museum. ... I used to play squash. But it HURTS when I RUN. It HURTS my LOWER BACK." (P1)*

*"I've flatted with others. With this particular time it did. They couldn't understand I couldn't do a lot of the housework because of pain. So I felt it was better to go." (P2)*

As proposed by Henriksson et al., (1992), most FMS patients have recognised that FMS symptoms impact on daily life substantially and they make changes to habitual and routine activities in order to adjust. Daily activities take longer due to the difficulties of getting started in the morning.

Turk et al. (1996) reported these alterations can change how one perceives oneself augment physical deconditioning and, hence, increase disability and psychological distress. Further, the experience of traumatic injury can change individuals' sensory functioning and perceptual processes (Turk et al., 1996). For example, FMS sufferers have elevated awareness of and response to pain, yet there is no evidence as to whether this change is due to physiological or psychological hypersensitivity (i.e. selective attention and sensory evaluation). Lautenbacher et al. (1994) concluded that such hypersensitivity involves both peripheral pathology (i.e. sensitisation of muscle nociceptors) and disturbed central mechanisms (i.e. hypervigilance).

On the other hand, long period of chronic pain can substantially influence sufferers' activity status and give them some time to adapt to their reduced capacities by readjusting daily routines, priorities, and pursuing new goals and interests. They learn to manage their most important daily activities, work shorter hours, and rearrange their lives to compensate for their reduced capacity.

The resilience of the participants in this study was observed when participants fought the consequences of FMS, learned to find substitute activities, and learned to reprioritise, modify, and pace their activities. Participants often mentioned their ability to compromise on certain tasks, for instance, some recreational activities. Consistent with Metcalf's (1990, cited in Feine & Lund, 1997) results, several participants substituted recreational activities with aerobic exercise to enhance their physical endurance and emotional wellbeing as well as reduce muscle stiffness, fatigue, and pain severity.

## ILLNESS IMPACT ON EMOTIONS

Two categories of illness impact on emotions were derived from the data: feelings about self and feelings about the illness, which are discussed separately below.

### Feelings about Self

Two sub-categories of Feelings about Self originated from the data: Control, Independence, & Vulnerability and Emotional Effects of Pain. These two sub-categories are discussed below individually.

#### **Control, Independence, & Vulnerability**

Refer section of perceptions of emotional state for feelings of control, pp. 123-4.

Participants' felt that one of the factors that influenced their feelings of vulnerability in a negative way was their loss of independence, which impacted their QOL. P8 reported having suffered tremendous mental distress and concurrent loss of independence. Although substantially limited in their activities, many of the participants (P2, P3, P4, P6, and P7) felt that they still maintained a certain degree of independence. However, they relied on external forms of health related assistance, for example, Home Help (P2), note-taking at school (P3), physical assistance like help moving furniture (P6) or heavy labouring (P7), and driving (P7).

*"Lost my own independence, LOST MYSELF. I used to ring my doctor quite often, also seeing him everyday when I was really bad. I did depend on him for a long time."* (P8)

*"Not as much. Because I try to get home help."* (P2)

*"I have to rely on people to take notes in class, but I am still pretty independent."* (P3)

*"Not a lot. I'm TOO INDEPENDENT ... unless I want something moved."* (P6)

*"I had to buy an automatic car. Some days I can't drive at all, so I can't go to work."*  
(P7)

These experiences are consistent with Kelley & Clifford's (1997) findings, that loss of control and independence, which participants categorised as part of QOL, were some of the most difficult aspects of having FMS.

Many of the participants mentioned feelings of vulnerability. For example, P1 stated:

*"Even when I tell the doctor how I am feeling, I would start crying because I feel vulnerable."* (P1)

In her study of general quality nursing care, Irurita (1996) identified vulnerability as the basic social-psychological problem shared by the patient participants. In other words, the transition from person to patient made participants feel susceptible to physical and/or emotional hurt, harm, or injury; and feel defenceless or weak with respect to self-protection, and open to possible assaults. Factors which increase the level of patient vulnerability include: (1) the severity, type, and course of the illness, injury or impairment, and related interventions; (2) dependence (which may be related to the illness, injury or impairment, or to diagnostic or therapeutic interventions); (3) power imbalance and abuse of power between the caregiver and patient; (4) lack of information or preparation; and (5) loss of identity or individuality. It is apparent that participants in the present study experienced negative aspects of many of these factors.

Consistent with Feine & Lund's (1997) findings, participants who were less anxious towards the future and more adapted to pain were those who have received some form of treatment intervention and better access to information. Having an illness with unknown aetiology and no cure, which, therefore, provided participants with no information, was the major source of vulnerability. That is, if you don't know what it is, then how can you deal with it. Supportive of Robbins et al. (1990) and McCracken's (1998) perspective, such feelings of vulnerability are predictive of both physical and psychological disabilities.

### **Emotional Effects of Pain**

All participants, except P1, reported being affected emotionally by their FMS experience, particularly from pain, as well as sleep disturbance and fatigue which originated from pain:

*"Sometimes I feel down and particularly when I am in quite a bit of pain and I haven't slept, I am just sort of quite drained really. ... because there is times I don't have as*

*much energy so you don't always feel as confident when you don't have enough sleep, you don't feel good about yourself. When you are kind of TIRED all the time, it seems to be a bit of bail to me. I DO [feel stink of not getting enough sleep]. because it really annoys me!" (P2)*

*"You can just REALLY get quite depressed about it and stuff. It's kind of HARD being in pain and stuff. ... That I am just getting so tired at school 'cos homework is almost like an impossible mission. ... Emotionally, I can go up on highs and lows all the time. I can still be quite happy most of the time, just occasionally I get a little bit of down or struggle with it and stuff. Sometimes realising it the whole kind of concept of the future is like the WHOLE life thing is quite hard to grasp. Like I am SIXTEEN, got to live until I am 80 or something. There's quite few years of pain to go, so that affects kind of your whole plan, so kind of emotionally. You just get quite depressed about it that you can't get out of the situation no matter how hard you try. You are kind of stuck. ... I'll have days when ANYTHING can just SET ME OFF CRYING. I don't know WHAT IT IS, you kind of just get past the 'what am I crying about' phase until you just cry for the sake of it, which is a bit weird. But I deal with it gradually." (P3)*

Three participants (P3, P4, P6) suffered a loss in appetite because of their fixation on their FMS symptoms as previously discussed in weight changes. Two other participants (P5, P7) attributed their loss of appetite to sickness rather than the pain.

*"There's times you just don't want to eat. You don't want to BOTHER. When I am really sore, that's the thing I am coping with and hunger doesn't come into the issue." (P4)*

*"I lose my appetite when get sick MORE than when I am SORE." (P5)*

Participants reported that social misperceptions developed as a result of a lack of knowledge about their FMS were harmful to their self-perception (refer Chapter Seven for Intervening Conditions). Specifically, three participants (P3, P4, and P7) reported lowered self-esteem. P3 reported diminished self-expectation as an outcome of lowered self-esteem. P7's blamed his low self-esteem on weight gain and limited physical functioning, including a shift in sexual activity (refer p. 144 for impaired relationship).

*"People don't understand so you think 'is this all in my head'. Self-esteem has taken A LITTLE BIT OF A BLOW. ... I don't expect as much for myself." (P3)*

*"REALLY LOW self-esteem, because I am FAT compared to before, because I can't have the sexual relationship with my wife that we USED to have, because the weight on top of me or vice versa. I can't walk and I can't do the PHYSICAL things I used to do, I*

*collected old cars and spend HOURS doing up old car, can't do that anymore. Then it makes you wonder what it's all about. It really does bring you down to earth."* (P7)

It is apparent in the present study that self-esteem is affected by FMS both positively and negatively. The negative side mainly came from not feeling validated, from not being able to help others, and from having to ask others for help. On the positive side, as participants learned to externalise the condition as something afflicting them, not as intrinsic to them, they began to feel positive about their efforts to fight its effects. Some believed the experience had made them stronger.

Unlike P1 and P7's consistent motivation towards tasks regardless of the consequences, four participants (P2, P3, P4, P6) reported FMS symptoms – pain, fatigue, and sleep deprivation in particular – affected their motivation. P3, who had suffered FMS from a young age was more pessimistic and felt a sense of *"what for?"* towards her plan for an academic career.

*"Motivation for WHAT! I am struggling through school. I planned going to university but whether I get there, I am gonna have problem sitting bursary so ... you are like 'what am I doing this for', probably not end up where I was going to anyway."* (P3)

*"I am not as confident as I used to be. Yes. ... I would have been doing papers and all sorts of things. But with the sleep deprivation and all those things, I can't do it."* (P4)

*"I still try a lot of tings. I still try and motivate, I end up with my shoulders, elbows, and backs are that bloody sore and I have a bloody good cry. But at least I tried."* (P7)

The literature indicates FMS patients frequently suffer from psychological distress, including negative feelings about and towards themselves, unhappiness and alienation, lower self-esteem, and self-confidence. This can be intensified by feelings of being misunderstood by medical practitioners, families, and friends due to the invisibility of FMS symptoms as previously discussed in medical and social support intervening condition of Chapter Seven. Further, probably because of the invisibility of FMS symptoms, sufferers do not always receive support from significant others, yet social support has been shown to be crucial for lessening stressful consequences from pain (Gaston-Johansson et al., 1990). The misconception of FMS sufferers as malingerers leads to alienation, lowered self-esteem, increased self-doubt, and increase of the illness severity (Raymond & Bergland, 1994).

Further, there was a decline in positive mood from morning to evening due to the rationale that the severity of pain and fatigue was worse towards the end of the day,

particularly during nights. Based on Affleck et al.'s (1998) findings that FMS patients that reported more progress toward social-interpersonal goals were more likely to improve in mood across the day regardless of any changes in pain or fatigue on that day. There was mixed reports from the current study. To some participants, the severity of pain and fatigue did serve as mediating factors, while others were not influenced by their FMS symptoms.

### **Feelings about the Illness**

Feelings about the Illness consists of two sub-categories: Worry & Pessimism and Emotional Distress. Each of these is examined below.

#### **Worry & Pessimism**

P3, an adolescent was apprehensive about her academic career, while P8's long history of depression had given her a pessimistic outlook.

*"a VAGUE plan of the future. I am WORRIED 'cos the next couple of years are crucial with education. It's pretty shaky, whether I can sit exams for bursary, get into uni and cope with the uni work. I am hoping I can get through it, but I may not."* (P3)

*"At the moment, I don't know if I've got a future, I just exist each day and just hope I can not cause too much problems at home and my kids, try to keep them as active and to live as a normal life without me pulling them back or something."* (P8)

#### **Emotional Distress**

Most participants (P2, P3, P4, P7, P8) reported feeling differently towards themselves as a result of FMS experiences. Primarily, negative perceptions of physical degeneration and emotional distress were discussed by all participants as a product of self-appraisal and physical debilitation.

*"I am more EASILY UPSET about things."* (P3)

*"Old, worn out, not much use to anyone. That's probably the most important psychological effect. I am no longer a sexual animal although mentally I want to be, physically I CAN be but it's that much pressure worth that much pain."* (P7)

Both Gaston-Johansson et al. (1990) and Robbins et al.'s (1990) comparative research indicated that FMS is related to a wider range and greater severity of somatic distress, without any real chronic disability, than rheumatoid arthritis. They further stated

that excessive worry about having a critical illness could influence FMS sufferers to misinterpret novel physical sensations to conform with pre-existing feelings of vulnerability to illness. Gaston-Johansson et al.'s (1990) study further suggested that FMS patients' negative and pessimistic feelings, lack of self-worth, and preoccupation with pain limited daily activities and future employment opportunities.

## ILLNESS IMPACT ON SOCIAL RELATIONS

Two categories of illness impact on social relations were derived from the data: social effects on participants and social effects on significant others. Each of these is discussed independently below.

### Social Effects on Participants

All participants reported suffering socially as a consequence of FMS. These social problems can be sub-categorised into a decline of social activity threshold (P1, P2, P3, P5, P6, P8), social avoidance (P4), social morbidity (P6, P8), and social isolation (P7, P8), which are examined individually below.

#### **A Decline of Social Activity Threshold**

Because of the physical impairment and extended ripple effects of FMS symptoms, most participants experienced a decline in social activity.

*"Socialising's definitely slowed down. I am still socialising with them on everything, just LESS FREQUENTLY."* (P3)

Although she claims she was not affected socially during adulthood, P5 encountered a period of social difficulties while living in Brisbane because the focus of social activity involved participation in a sports club, which meant a greater risk of injury to her.

*"very difficult meeting people and one way of meeting people was sports club, which I couldn't join. That has affected me entirely because I just injured my knee."* (P5)

#### **Social Avoidance**

P4 avoided social interaction when initiation was required. This led to a personality change (refer p. 151 for personality shift) due to the decline in her confidence and motivation.

*“where I need to ring someone else I will try to put it on Tony to make the phone call. I don’t want to make the effort to contact people. Yeah (more introverted). Initially because of the pain from injury and the lack of being able to do things. The last two years, because of lack of confidence and motivation, knowing it’s likely to hurt.” (P4)*

In a comparative study that focused on the characteristics of the social networks of FMS and rheumatoid arthritis patients, Bolwijn, van Santen-Hoeufft, Barrs, & van der Linden (1994) reported that FMS patients’ social networks were more restricted. This was due to an absence of initiative to sustain and establish relationships.

### **Social Morbidity**

Social morbidity (P6, P8) and social isolation are the more extreme end of social consequences. Social morbidity refers to a cessation and/or severe decline in social activity to a level where socialisation becomes a highly infrequent event. P8 was one participant who exhibited qualities of social morbidity. Because of P8’s job transition, she had been involved with different cohorts.

*“I am still in contact with only ONE of my members of my team. ... I am not with my rescue team, I’m not at that age group anymore. A lot of friends have drifted away.” (P8)*

According to Bolwijn et al.’s (1994) results, the limited number of networks seems to disproportionately lie within the family and intimate friends. Further, these networks were closed in nature and restricted by geography.

From the aspect of psychosocial effect, consistent with Bolwijn et al.’s (1994) comparative results, participants lacked initiative to maintain and establish relationships with people other than family members and close friends because the general misunderstanding of their conditions. Participants eventually desensitised to social effects over time and they would not jeopardise their conditions for such issue, and therefore, loss of social life was not of great concern to them.

### **Social Isolation**

Social isolation may be defined as a state of detachment, segregation, or withdrawal from interpersonal interaction and associations in situations where social interaction is readily accessible. Two participants (P7, P8) exhibited social isolation as a direct result of prolonged illness. Another reason for P7’s social isolation was through his colleagues’ lack

of attention during his illness. P8 reported 'divorcing' herself from social interaction with friends and family, including her husband, as a form of self-protection.

*"Don't have anything to do with them [colleagues]. ... because when I had my operation I was at home, tied up in bed for four months, NONE of them came to see me. NONE of them came around to offer to mow the lawns or anything. I haven't got it and I DON'T want any. DON'T need any. Life is pretty plain and straightforward."* (P7)

*"I am finding it HARD to open up to you because I am thinking you may be sitting there and thinking 'oh, she's just another nagging'. ... It's hard to let people into the space. It's been so long that I've put this wall around myself for what I've gone through."* (P8)

Overall, as outlined by Henriksson & Bengtsson (1990), participants did describe psychosocial difficulties as an overall effect of impaired psychological functioning and social status, which, in turn, were induced by diminished physical work capacity.

### **Social Effects on Significant Others**

This categories consists of three sub-categories, which were derived from the data: impaired functioning as parents, impaired family functioning, and impaired intimate relationships. Each of these is discussed separately below.

Those in close association with FMS suffers tended to make oblique adjustments to accommodate suffers' needs. For instance, the family and friends of P3, P4, P7, and P8 actively altered their routines to accommodate participants' needs as previously discussed in relation to the Social Support Intervening Condition in Chapter Seven and the Seeking Help Coping Strategies in Chapter Eight.

### **Impaired Functioning as Parents**

One of the effects of FMS was impaired parental functioning. For instance, P4 and P8 expressed their regrets at being unable to interact with their children as they had prior to their injuries. Specifically, their interaction with their children had shifted from active to passive involvement, with a concern that their children's emotional wellbeing, development, and relationship with their parents could be functionally damaged.

*"It does have an effect on my relationships with the family. I've become much less hands on. Things like going out and doing things with the children. I am more likely to sit and watch them. It's affected in that we all had to modify the way we interact."* (P4)

*"It would probably have affected them. It must be hard for THEM. I like to do MORE for my kids than what I am doing now. ... hard on the kids too at night because I become VERY tired and they ask me sometimes about their homework, I say 'go to your father'. I am pushing them away ... I HATE doing that."* (P8)

As identified by Neumann & Buskila (1997), most participants agreed upon the adverse effects of FMS on family life. Those who occupied a mother role were particularly concerned with their children's upbringing.

### **Impaired Family Functioning**

Three other participants (P3, P6, P7) commented on how their family members' lifestyle had changed. Specifically, family members' helped participants cope (P3, P6) and/or provided emotional support (P3, P6, P7). Through the FMS experience P6 and her children became more attached.

*"They really understand it, fully now. They know I need rest, I get sore, I could get into a bad mood quickly, they cope with it. They are helpful. We've become very close."* (P6)

This agrees with previous research where it was found that FMS adversely influences the family life of FMS patients (Neumann & Buskila, 1997). Relatives of FMS patients, especially female relatives and those with undiagnosed FMS, were more dissatisfied with aspects of life and experienced more functional limitations than healthy control subjects.

### **Impaired Intimate Relationships**

Because of the physical effects of FMS, two participants (P4, P7) further reported concerns about intimacy involving physical contact with their partners. P7 expressed of the emotional distress it inflicted on his wife.

*"The sexual relationship, it definitely has changed. Has this not come in to complicate things, our sexual relationship will be very different to what it is now."* (P4)

*"It HAS HAD a DEVASTATING effect on ME and MY WIFE. ... no longer affectionate towards her. I don't let her hug me and that's progressed to I don't let her kiss me because it leads to other things. ... I probably made her feel quite rejected."* (P7)

P8's coping strategy was to *"keep it to myself"*. Because of this, P8 experienced recurrent intimacy, trust, and communication issues with her husband. This was exacerbated

*"put it DOWN to antibiotics, because ... to clear the infections and stress because I was working LOTS of hours. I resigned to get away from work. I was quite tired."* (P5)

Changes in job status led three participants to engage in voluntary (P2) and part-time (P7, P8) work, which served to help them manage their conditions through distraction (refer Chapter Nine for coping strategies).

*"some efficacy work with the members of social services for Income Support."* (P2)

*"I forced myself back to work. I was still on two hours a day."* (P7)

The youngest participant (P3) expressed her concern for her academic career. Because of her reduced energy levels and inability to engage in activities that required prolonged static positions, P3's performance declined below her normal standards.

*"... doing exams, I am not 'cos I CAN'T SIT OR WRITE for that long. ... based on assessment work. I am SO BEHIND. It can be pretty DAMAING. My marks have slopped because I am SO TIRED. ... don't have the ENERGY to do the work."* (P3)

FMS does impact on the ability to work. For the majority of people suffering from FMS, the ability to work depends more on how the task is performed than on the severity of the condition (Henriksson et al., 1992; Raymond & Bergland, 1994).

Except for a small group of patients with severe FMS, most FMS sufferers are able to maintain their jobs. However, research findings report that the high level of unemployment among FMS sufferers is primarily due to ignorance of the disability by the sufferers themselves and others (i.e., employers) (Cathey, Wolfe, Kleinheksel, & Hawley, 1986), which was previously discussed in Social Support Intervening Condition in Chapter Seven.

### **The FMS Employees: Type A Personality**

Some participants appeared to have the characteristics of Type A personality. P1 and P2 engaged in activities for prolonged periods and intensities that predisposed them to FMS and injuries that worsened their condition (P1, P2). For instance, P1 reported excessive work application:

*"Workaholic. I can do a million things at once. ... I'm a very hard worker. I overdo it. ... I was really good at everything, that does everything."* (P1)

Three participants' (P2, P6, P8) revealed a stronger tendency towards adherence to task completion. This 'drive-to-complete' behaviour (P2) or 'adaptation of behaviour to complete tasks' (P6, P8) often continued despite impaired physical function.

*"On a bad day, I wouldn't cancel voluntary work. Because I've committed to that, even though I might not be feeling 100%." (P2)*

*"I can DO them, but they take a lot LONGER to do." (P6)*

*"If I do something I always get 100% from it. I like to complete a task that I start. If I go out in the garden, I put in my mind this is what I want to get done, but I will only get half way and I start struggling, but I push myself to get what I aimed for at the start." (P8)*

A tendency towards perfectionism (P2, P8) and belief in punctuality (P8) are the other two examples:

*"I don't think it's (higher standard) as bad as it used to be though. I used pretty much to be an perfectionist." (P2)*

Although P2 did not directly establish a link between perfectionism and her FMS condition, it appeared evident that her Type A personality could have prompted her into continuing with repetitive types of work and excessive work application by *"work[ing] a lot of over time"*. This seemed consistent with the primary cause of her FMS (i.e. work-related injuries).

P8's perfectionism was acknowledged by her friends and colleagues who had commented (hearsay) on her high standards and drive to complete. This was also evident in recollections of her expectations of herself in her work and leisure activities. She could not tolerate mistakes or imperfections in her work.

*"My friends have told me I have got a higher standard of what needs to be done. ... knitting, if I make a mistake, I can't leave it and cover it up, I've got to fix it. ... I always tell my ladies if they are not happy about something, tell me. I like to know. I've got to do something. I don't know sometimes if I tried 150%, especially safety standards, perhaps I MAY go overboard." (P8)*

P8 burdened herself with additional stress when she was accused of having missed some psychiatric counselling sessions. In order to prove her total attendance at psychiatric counselling, she conducted a comprehensive investigation of her attendance records and proved fruitful in that she proved that she had attended all sessions. This illustrates her need to be seen as performing in a 'perfect' way.

*"That finally got proven. ... I carry a DIARY with me. I've got everything that I do. I DO believe punctuality, if I've got an appointment, I do my best to get there." (P8)*

Lastly, one participant (P2), through her participation in competitive sports, repeatedly injured her wrist to the point of permanent weakness. She clearly indicated the

need to participate in normal activities despite the constant presence of pain. She also reported high risk-taking, which was particularly relevant to non-work-related accidents and activities.

*"Willing to give anything a go." (P2)*

Contrary to the fallacy that FMS sufferers are neurotic and advantage takers, Goldenberg's (1989, cited in Kelly & Clifford, 1997) proposed a non-stereotypic personality for FMS sufferers. Clinical Studies by Smythe (1985, cited in Boissevain & McCain, 1991b) and Waylonis (1992, cited in Raymond & Bergland, 1994) indicate that FMS employees frequently exhibit compulsive, perfectionism, and obsessiveness behaviours in regards to their personal appearance, job performance, and punctuality. They are demanding of themselves and others, and dislike the use of their illness as a "crutch".

Many of these qualities are in accord with the Type A personality proposed by Friedman and Roseman (1974, cited in Weiten, 1992). According to these authors, individuals with a Type A personality are typically ambitious, hard-driving perfectionists with high motivation. Moreover, they possess a stronger than normal drive to accomplish goals, which sees them been drawn to competitive careers with power and recognition (Burger, 1993; Weiten, 1992). Type A's routinely attempt to do several tasks simultaneously and commonly fall into the category of workaholic's.

In the present study, contrary to Goldenberg's (1989, cited in Kelley & Clifford, 1998) suggestion that there is not a stereotypic personality for FMS sufferers, personality appeared to play a causal, or at least a mediating role, in the onset and maintenance of FMS. The characteristic behaviour of Type A personality predisposes individuals to overexert themselves physically and psychologically, which might lead to injuries or trauma precipitating the onset or increasing the severity of FMS symptoms. Most participants in this study exhibited various characteristics of Type A personality including hard-driving perfectionism, workaholism, obsessiveness, drive to accomplish and obtain set goals, motivation to overcome obstacles.

#### **[New Finding]: Personality Shift**

Several participants reported that the experience of FMS symptoms and pain had changed their personality in general. Considering the criteria of Type A personality, three participants (P2, P6, P8) reported to have mellowed consequent to physical deconditioning, although P2 and P8 still engaged in over achievement type behaviours. Both P3 and P8

believed themselves to have become more serious towards things. P6's attitudinal and personality shift was partly due to her prescribed medication, Prozac, which she has been taking to assist with depression and relaxation.

*"It's [high standard] not as bad as it used to be. I used pretty much to be an perfectionist. I STILL STRIVE for that, but not at the same level because this illness has damaged me in ways that I can't be as motivated as I was before."* (P2)

*"Slowly starting to relax. ... I am NOT NOW [perfectionist]! I am not the same self, but I am a lot better. ... I've actually SLOWED r-i-g-h-t d-o-w-n, I am more inclined to sit and rest now than when I used to do everything I want to do and it had to be done. Now, if it doesn't get done, too bad. The whole attitude's changed. ... since Dr. Wong's wound me down, people don't like it or I don't go out, I don't really CARE!"* (P6)

*"I am a bit more serious."* (P3)

The youngest participant (P3) considered her FMS experience as educational and maturing because she felt it had helped to mould her personality during adolescence. One outcome of this seemingly early maturation was that she felt more aware of herself and other people, particularly their personal problems.

*"I am more aware of other people's problems 'cos there are friends kind of let me down in that regards, so I've kind of helped other people with their personal problems or physical pain or something. I've grown up a bit since I've had this 'cos it's kind of an eye-opener really to see the life doesn't always work out how you want it to."* (P3)

### Shifts in Future Occupations

The overall life effects, including daily functioning, emotional, cognitive, social, occupational, financial, and coping outcomes have changed participants' future prospects and future life goals.

*"Initially because of the groin pain, ... I actually crashed physically. ... and things started happened like that, so I ended up with financial stress, physical stress."* (P1)

Some participants (P1, P4) had contemplated shifts in future professions, while others were contemplating adjusting their working status from part-time to full-time or vice versa (P2, P7) or furthering education (P5). The youngest participant (P3) was pessimistic with considerably reduced self-efficacy.

*"Classroom teaching wouldn't be an option for me. Adult teaching or teaching English as a second language or small group work. Either that or motivational training."* (P4)

*"I hope at the end of this month to go back eight hours a day." (P7)*

*"go back to full-time study next year. Maybe osteopathy, maybe business study." (P5)*

*"Employment is a bit of shady area for me. I probably WOULD BE capable of getting a sickness benefit, but I PREFERABLY, career wise, I wouldn't really want to spend my life like that. DEFINITELY worry about who's gonna employ me." (P3)*

Because of the physical and economic implications of employment for FMS patients have had to consider their vocational status. The effects on occupation reported by participants are similar to those indicated in studies by Becker et al. (1993) and White et al. (1997) of chronic pain sufferers. Employment issues were of considerable concern. Three patients were employed despite reported symptoms. Almost all participants in this study reported the influence of FMS on their work situation. For instance, five stopped working because of their FMS symptoms while most participants reported high possibility of career changes due to their impaired physical health.

Other than formal employment, participants also mentioned other energy demanding roles, such as mother and housekeeper. In the present study, four participants were married and five had children. When the housework was shared by their husbands or older children, the women experienced stress and feelings of guilt and personal failure.

The non-working participants also mentioned spending time in largely sedentary activities such as watching television, socialising with the family, taking care of children, or reading. Most of the participants reported regular physical exercises with preference for light exercises, such as walking or swimming as previously discussed in relation to Coping Strategies in Chapter Eight.

### **Financial Effects**

Most participants reported substantial financial losses due to their physical condition. The reasons for loss can be sub-categorised into **financial restriction from inability to work** (P1, P2, P3, P4) and **from constant medical charges** (P3, P6, P7). P1 considered the whole situation to be a *"vicious cycle"* because her physical deconditioning lead to her being unfit for employment, which in turn lead to financial constraint, that provided her with further stress.

*"Because I am unable to work. ... all due to the pain of fibromyalgia has caused." (P1)*

*“I am losing out FINANCIALLY, BIG TIME ‘cos all those surcharges on the medical cost. I am too young to get Income Support, I lost any income, really horrible.” (P3)*

Both treatment costs directly associated with the condition and the opportunity cost of lost income are substantial. Compensating sufferers for work loss has proven to be exceptionally costly when compared to pain treatment costs. Patients and families also suffer from the economic impact of pain (Ferrell, 1996, cited in Linton, 1998).

As mentioned earlier, the majority of participants in this study were unemployed and therefore have relied on financial support from families or government agents. Additionally, however, most participants reported having difficulties in claiming financial compensation, mainly from ACC. In accord with Cathey et al.’s (1986) proposition, participants attributed limited access to any sources of financial aid as well as their employment rate to public ignorance of the extent of their physical limitations. This theme tied into the loss of independence, which participants found difficult to cope with.

Interestingly, P8 seemed less affected by financial concerns because one of her coping strategies involved continuation with activities to keep herself occupied as a distraction. Therefore, she maintains her part-time work while receiving a disability allowance.

*“Not so much. What I work for I am still hoping contribute to the household. My little wages help to pay school fees and get the kids their things.” (P8)*

## **ILLNESS IMPACT ON RELATIONS WITH HEALTH-CARE SERVICES**

Four categories of illness impact in relation to health-care services were derived from the data: satisfaction with medical practitioners, satisfaction with diagnosis, satisfaction with medication & treatment, and satisfaction with accident compensation commission services. Each of these is discussed independently, although they are closely interrelated.

### **Satisfaction with Medical Practitioners**

Six participants (P2, P3, P4, P6, P7, P8) expressed their confidence and trust in their own GPs. This was largely because their medical practitioners exhibited a more attentive attitude to their requests and concerns.

*"REALLY GOOD. ... sent me to the specialists when I feel something's wrong." (P3)*

*"I went to see Dr. ... who has helped me got better." (P6)*

*"My GP stuck with me the whole time. ... he's been very supportive." (P8)*

However, participants generally expressed negative perceptions of medical practitioners and institutions as a consequence of recurrent treatment failures (P1, P6, P7, P8) or professional mismanagement of their cases (P2, P4). Both P1 and P8 shared a similar distrustful, guarded disposition towards psychiatric practitioners as a result of conflict, in perspectives on their conditions between themselves and their psychiatrists.

*"Because the counsellors were looking for the things that I was doing that offended people. I didn't trust the psychiatrists. ... they are just selling drugs ... What really, really irritates me is that I am going for exactly the same thing for years and years and he still charges me FULL price every time I go. I don't TRUST DOCTORS." (P1)*

*"Even if they are not the ones to do the follow-up treatment, they could've at least referred me. I don't see by going to the specialist is going to make any difference." (P2)*

P1 and P7 became doubtful about their medical practitioners' ability to treat FMS due to their repeated diagnostic and treatment failures. These feelings were increased by the expenses incurred through medical charges.

*"paying them for me to get worse. ... a MULTI-million dollar business. The government is in it too. ... suffer the consequences of cost, stress for that cost." (P1)*

P1 and P5 further specified their overall annoyance with medical-care practitioners. They were both *"annoyed"* by the improper medical treatment, which was compounded by what they perceived as a negative attitude and poor explanation of their condition from their medical-care practitioners. P1 described a concern that her physical deterioration, which resulted from treatment failures, would have a carry-over effect on her daughter's future wellbeing.

*"I am annoyed because I went to experienced, trained, and expertised of people to help put my body back into order and that's never has happened. I AM worried that it's gonna affect my daughter in the long-run. ... I am really annoyed with all the doctors because this wouldn't have come this far if they have taken me seriously in the very beginning. Or if they had treated me better ... totally irresponsible, have never ever done their jobs, protected their patients against what can happen." (P1)*

Two participants' (P2, P5) annoyance about their specialists' apparent negligence was exacerbated when they were diagnosed without further explanation or referral to

rehabilitation programme(s). P5's irritation with her specialist was aggravated when it was revealed in a medical advisory manual that the medical staff should provide patients with a comprehensive explanation of their condition.

*"They didn't suggest rehabilitation or to refer me. ... I WAS (annoyed). I thought the specialist should've directed treatment."* (P2)

*"He didn't say anything AT ALL. ... I was even more miffed when the notes from the medical book stated the doctor should EXPLAIN well, which mine didn't do."* (P5)

In summary, the disappointment with medical-care practitioners stemmed from inadequate explanation, insufficient medical treatment, and inadequate provision of information. This caused patients to develop doubts and scepticism regarding medical-care practitioners' competence in general.

*"It's SURPRISING. ... medical professionals I am dealing with really have NO IDEA about it ... you know MORE than they do. It's kind of horrible."* (P3)

*"I've got DOUBTS with the chiropractor."* (P8)

As a result, two participants (P1, P8) reported a high level of apprehension about professional assistance when experiencing severe pain.

*"AFRAID he's just saying yes. Does he actually believe it's FMS or does he think I'm neurotic ... and because there is nothing you can do for FMS."* (P1)

*"takes me a long time to ring the doctor. I've gone through bad flu and swallow pain, I didn't want to go to the doctor, think he's gonna tell me there is nothing there!"* (P8)

Patients' satisfaction with medical health services has become the focus of recent research attention but conclusions are derivative and largely unfound (McCracken, Klock, Mingay, Ashbury, & Sinclair, 1997). First, patients' satisfaction with health-care services indicates some treatment effectiveness. Further, patients who are satisfied with treatment exhibit more behaviours that improve or maintain their health. Finally, the level of satisfaction is inversely related to a patient's tendency to use legal action or make formal complaints against medical health-care services. Chronic pain patients who suffer from severe depression are more likely to be dissatisfied with contemporary medical treatments.

It appears there is a need for the public health sector to improve the provision of health and social care benefits to FMS patients. Similar to chronic pain patients' reports in Astin et al.'s (1996) research study, in this study, the majority of FMS participants attributed their suffering partially to insufficient resources and care provided by medical

practitioners for pain relief. Most participants experienced delay and complications when they sought referrals and treatment intervention as previously discussed in relation to Intervening Conditions in Chapter Seven. Their dissatisfaction with health-care services is consistent with the positive correlation between treatment effectiveness and satisfaction with health-care services found by McCracken et al. (1997). In this study, participants' treatment satisfaction was negatively associated with impaired mobility, depression, the number of medical-care practitioners consulted, delays and complications, limited access to pain clinic treatment, and the frequency of visits to medical professionals for pain. Their treatment satisfaction also predicted their subsequent use of health-care services.

Further, participants in this study who reported improvements in their physical and psychological wellbeing were satisfied with medical-care staff who attentively assisted patient needs. These participants, therefore, engaged in activities that are more constructive and made fewer complaints. Because part of participants' depression was derived from medical-care practitioners' ignorance, lack of interpersonal skills, and ineffective medical treatment intervention, the more depressed sufferers exhibited greater level of dissatisfaction towards health care in general.

### **Satisfaction with Diagnosis**

Participants generally described a prolonged period of medical consultation before receiving a diagnosis of FMS. Diagnoses provided a sense of relief from negative emotions and doubt. It appears that an accurate diagnosis of FMS provided patients with validation of the existence of their symptoms after prolonged periods of misperception. This was discussed in relation to Social Support Intervening Condition in Chapter Seven. Once diagnosed, the knowledge of 'what it is' could be directed into 'what to do' or 'how to deal with it'. From this perspective, a proper and accurate diagnosis was perceived by all participants as a critical step of the healing process. All participants believed they then could continue with their lives and learn to manage the pain and symptoms. Four participants (P2, P3, P4, P7) felt a sense of relief when they received the diagnosis. Another three participants (P4, P6, P8) regarded the diagnosis as an opportunity to make sense of their condition since they now had a "*name/label*" for it, despite its untreatability. P6 and P8 found that receiving diagnoses conquered the impression that their symptoms were "*all in my head*".

*"That was a sense of relief, anger, helplessness. It's a grieving process." (P4)*

*"I had a label. There was a reason behind it." (P4)*

*"... people were getting to think it was all in my head and I was pleased that at least we knew what it was. I didn't care if they couldn't cure it all, couldn't treat it." (P6)*

P8 believed she suffered unnecessary depression and self-doubts because of inadequate diagnosis. She believed an accurate diagnosis from the onset would have equipped her better to understand and deal with her condition.

*"it [suicidal thoughts] may not be as strong. ... may help me better because it's finally a name to something and the symptoms DO correspond with what they was FMS. If I knew earlier about FMS, the extra stress might not have been as bad." (P8)*

As a result of her experiences with diagnoses, P8 lost confidence in conventional medicine and medical practitioners as well as herself.

*"I still have DOUBT in myself, because it's only a new thing and it's just another LABEL. I still don't know what direction I am going and it's a weird feeling." (P8)*

Two participants (P5, P8) identified negative emotional reaction to receiving the diagnosis, but with conflicting reasons. P5's negative reactions arose from not receiving adequate explanation of the condition from the specialist, while P8's emotional reaction resulted from receiving acknowledgement of her agonising experience.

*"I was PRETTY UPSET when I first heard and I was concerned that I didn't know what it was because of being told I had something and it had a horrible name." (P5)*

*"when I got home, that's when it really hit in and I cried that night. It's taken EIGHT YEARS for somebody to say something else, other than depression." (P8)*

During the course of seeking medical professional support, patients typically encountered diagnostic discrepancies and scepticism from their general practitioners as to the validity of their FMS. It was quite common for patients to change their doctors repeatedly after the onset of FMS.

*"I had to change doctors. Because the doctor in Fielding was treating me as if I was neurotic, a druggie, and I wanted tranquillises. I HAD SO MUCH TROUBLE." (P1)*

*"I had told him that the reason why I had left his practice. With all of us with the attachment and everything, my whole family had left his practice." (P4)*

## **Satisfaction with Medication & Treatment**

During the trials of medications and/or other treatment, participants variously experienced adverse side effects (P1, P2, P4, P8), or improvement (P1, P3, P5, P6, P7, P8), or no change (P6, P8) in their conditions.

*"I have received SO MUCH medication that wasn't necessary, I believe my immune system was broken ... My body has got worse. I've got tablets aglow. It's the tablets contributed to it. ... taking iron supplements. They make me sick, give me cramps, heady, I feel lousy. I do not have ANY good feelings until I stop taking them."* (P1)

*"I can relax more. ... Prozac's done me the world of good."* (P6)

*"had the carpal tunnels done to stop it (numbness and tingling), but it hasn't."* (P6)

In addition to alternative as a medication, P2, P4, and P8 sought resolution and relief for their pain from alternative medical treatments including physiotherapy, acupuncture, and/or chiropractic treatment. Unfortunately, these treatments offered no relief and, in some cases, exacerbated their condition:

*"Physio never has helped much. ... It did that [minimise pain] occasionally and it will come back again. ... I have a bit of chiropractor treatment, it made it worse."* (P2)

*"I wasn't coping with muscle strengthening programme. I would suffer unduly afterwards, pain all over. It worked the opposite. ... tried acupuncture and I went through the same thing. All the electrical impulse stuff is not working with me."* (P4)

Based on the outcomes of the trials of medications and/or treatment, three participants (P1, P4, P5) were sceptical about the effectiveness of medication and treatments. They had an increased preference for self-management.

*"WHATEVER IT IS, unless it knocks you out completely, and after the first couple of doses they just don't work."* (P1)

In addition, two participants (P1, P5) felt that they had reached a point of saturation in regards to their former reliance on antibiotics. Instead, they chose to ignore antibiotic benefits in favour of being drug free.

*"Never ANTIBIOTICS. That is what has helped the DEgeneration."* (P1)

Five other participants (P2, P3, P6, P7, P8) accepted the reality that they became dependent on medical interventions. Two participants (P2, P3) declared their reliance on sleeping pills is as a means to manage sleep deprivation. P2's participation in a aerobics physiotherapy programme intervention aimed at minimising pain indicates that she preferred these programmes over medical aimed at pain management. This demonstrates

P2's loss of faith in conventional mainstream medications, with a preference for alternative treatments.

*"I'm not 100% happy with it but then if I need to sleep, I guess I got to the point where I just need to do something. ... That's why I am waiting to see if these exercises are gonna be helpful for that (minimise pain). I am gonna try it anyway."* (P2)

Despite adverse reactions and general reluctance to take medication, P8 used medication to manage her pain during episodes of severe pain.

*"I don't really want to go back on too much medication because I don't want to go through withdrawal symptoms again. ... I felt like a pill-popping machine. ... [the pain] did get that bad, I wanted myself on it. I needed something else to cope."* (P8)

P6 and P7 reported Prozac (antidepressant) as an effective medication for minimising the severity of their depression. Both were optimistic about its effectiveness once they overcame the side effects.

*"... the depression would always be there if I wasn't on the Prozac because when you realise there's a lot of things you can't do, you start getting SICK of it and that's when you start to get depressed."* (P6)

P6 identified the beneficial effects of cigarettes for her condition. Smoking allowed her to endure the recurrent physical and psychological disturbances, despite its detrimental physical effects.

*"Yeah [cigarette as part of medication]. Because my husband gave up and I said 'I'll give up' and he said 'no, you won't'! He said 'I want to live a bit longer'!"* (P6)

Although not in favour of mainstream medication because of their previous experiences, two participants (P1, P4) were enthusiastic about herbal and alternative medication despite its expense. Having tried mainstream medication, they were now willing to try something new if it meant a possibility of improving their conditions and general quality of life.

*"something in the herbal or the alternative lines, I would take them. ... If it is something that's gonna help me and give me back some things I used to have, to hell with the financial cost. ... emotional benefits, physical benefits."* (P4)

Literature indicates that although medications can be helpful for some aspects of FMS in the short term, medical histories and personal testimony confirm that drugs do not offer significant long-term relief from pain. For instance, while medications used for the treatment of acute pain reduce the severity of the physical symptoms, they frequently

add to psychological symptoms through increased depression when given over prolonged periods (Gildenberg & DeVaul, 1985). Particularly detrimental are narcotics and depressant tranquillisers. Other problems include patients taking medication only to comply with doctors' orders or from a need to feel they are doing something about the pain. Further, prescription of drugs symbolises to patients the doctor's belief that they have an illness which requires treatment. Furthermore, most chronic pain patients are taking or have taken inappropriate medication (Gildenberg & DeVaul, 1985). Gildenberg & DeVaul (1985) further reported that patients frequently overmedicate on doctors' instructions though misdiagnosis of their condition. Pain patients tend to be medication-oriented and may seek medication from more than one physician.

Participants typically sought consultation and treatment from medical practitioners for relief from pain. Provision of treatment symbolised action, even if ineffective, as both parties (patient and GP) believed they were doing something about the condition. Despite these beliefs, Gildenberg & DeVaul's (1985) found that most chronic pain patients described treatment interventions to be ineffective in terms of reduced symptom severity. Contrarily, participants in this study whose treatment worked were reluctant to take increasingly larger dosage of medication, which is consistent with Ediger's (1991) findings.

### **Satisfaction with Accident Compensation Commission Services**

Of the four participants (P3, P4, P7, P8) who have been involved with ACC, three (P3, P4, P7) reported negative perceptions of ACC. P3 was negative towards ACC because of their insufficient compensation payments and because she had made numerous unsuccessful claims for ergonomic furniture for pain relief. Both P3 and P4 were more antagonistic towards ACC after the nation-wide coverage of its attempt to withdraw compensation eligibility for FMS patients. Both were determined to pursue legal action if their claims for compensation were declined. P7's antagonism arose from a total absence of financial support from ACC.

*"pretty negative towards them because they're meant to pay me 80% of my formal wage, I'm getting half. ... cos they stuff me around with chairs and I find ACC hypocritical of how half page in the ads say how amazing they are and really they are not.... If I took them to court I probably can still win at this stage."* (P3)

*"ACC, all powerful. I have some really bad opinions of ACC. ... I will take them to every court in the land if they try to stop funding me because I have FMS."* (P4)

*"ACC is the meanest son of bitch on the land after Bill Birch and Jenny Shipley."* (P7)

### **[New Finding]: Medical Practitioners' "Changeable" Diagnoses in Response to ACC's Policy**

A common reaction from patients' GPs to ACC policy was a deliberate mis-diagnosis of their FMS as a ACC-recognised chronic pain condition. This strategy appeared to have been adopted by GPs to circumvent ACC's Intentional denial of FMS claims.

*"doctor will advise them 'don't claim under FMS, do it under lower back or chronic pain or how are you gonna treat yourself'."* (P4)

*"... he was happy with the MYOFACIAL pain syndrome. He may be thinking the ACC way because he DID turn around and said 'ACC will not cover FMS'."* (P8)

## **GENERAL IMPACT OF LIVING WITH CHRONIC PAIN**

Two major categories of general impact of living with chronic pain were derived from the data: overall perceptions of FMS experience and effects on QOL, which are discussed separately below.

### **Overall Perceptions of FMS Experience**

The overall experiential-learning process of dealing with FMS symptoms and pain also developed several participants' (P3, P4, P5, P6, P7) sensitivity towards their own physical health and ageing (P5, P7). Two participants (P3, P4) stated an increased need to predict the consequences of their actions before initiating them. For example, after years of hardship fighting FMS and developing strategies to alleviate its severity, P6 demonstrated a determination to protect herself from aggravating her condition.

*"More negative attention to my health. Now, I am coping with my health. That's almost as if I am back peddling. ... where is now, I actually have to plan to think 'can I do it', if I can do it, what would the consequences be'?"* (P4)

*"I am CONCERNED as I get older. I don't know what I am going to have problems with rheumatism in my joints and I DON'T KNOW."* (P5)

*"NO WAY I'll jeopardise my illness. I'll fight with tooth and nail, I avoid ANYTHING that'll make me be like that again. ... I PROTECT myself more. I wouldn't go out of my way to do anything that might get me in pain."* (P6)

The majority of participants (P1, P2, P3, P6, P7, P8) considered continuous pain as the most salient aspect of FMS condition. P4 considered coping and the adjustment of personal values and goals were the most significant while P5 perceived "NOT KNOWING" to be the most difficult.

*"Coping. It's basically what I do. ... gone from an intellectual person relying on my mind to a physical person being aware of my physical being. ... the biggest shift."* (P4)

*"Pain, headache's been with me the WHOLE time. ... live with PAIN is the hardest."* (P8)

Participants' perceptions of the FMS experience were strongly negative. Five participants (P2, P3, P6, P7, P8) concluded that their extended exposure to FMS symptoms was agonising and disturbing.

*"I generally don't find it a pleasant experience. When I am in pain, I want to ESCAPE from it, but you can't. I have to live with it. Can feel pretty FRUSTRATED."* (P3)

*"It's the only TRAUMATIC thing's happened, physical or emotional."* (P7)

Three participants (P4, P7, P8) associated their FMS experiences with "old age" because they perceived that the various physical and psychological symptoms were similar to "old age".

*"Old age. Old people get ringing in the ears. sore joints, lose control of their bowel and bladder. Walking stick, old age. Get my wife to pull me out of the chair, old age. ... It [short-term memory loss] helps to relate to being old."* (P7)

However, one participant (P6) did not perceive herself differently and accepted the transition in her physical experience and capacity because she has adapted her changed circumstances. For instance, her condition and coping appeared to have improved once her suspicions about her illness were confirmed.

*"I used to get SICK of myself because I knew something was wrong but I didn't know what it was. I have to manage it the best way I can. I've learned what to expect and not to expect as long as they leave me and my medication alone, I am quite happy."* (P6)

Overall, most participants considered their futures with optimism (P1, P2, P3, P4, P6, P7) in terms of managing pain, their FMS, and 'getting on' with life.

*“adjust my future goals. I started to realise this could be life threatening. ... my body was DEgenerating. ... My whole f-o-c-u-s was to buy a house to have a secure FUTURE for my daughter. ... I never see the end of the road. I would just go through the adjustments. Be positive. My body is broken, but I still want to do everything.” (P1)*

*“I don’t want it to stop me from doing things and I will fight that. If I can find things to ease the problem I will do so. I’ve come to acceptance, I’ve got it for life and I have to cope with it. I have to take a lot of it on myself because it’s an unseen disability.” (P4)*

In summary, all participants were frustrated with their experiences of living with chronic FMS pain. Most of them reported to be “sick of it” and/or “getting used to it”. However, they also considered pain as part of their lives since it affected all aspects of their daily lives since the onset.

### **Effects on QOL**

All participants reported FMS symptoms, pain in particular, had affected various aspects of their quality of life (QOL), including financially, physically (P1, P2, P3, P7), they experienced loss of control over life (P4), and/or loss of life enjoyment (P4, P8). P1 and P2’s financial limitations were the result of physical deterioration, which ultimately precluded employment. P7’s diminished leisure activities were a consequence of physical restraint and the financial burden of ongoing medical expense. P4 felt a loss of control over her personal health because of her reliance on medical professionals and institutions to manage her health. Both P4 and P8 reported that much of their enjoyment of activities had been reduced. They now participated out of obligation. P3 stated that chronic pain and impaired energy reserves effectively altered numerous aspects of her life, while P6 has modified her life in response to FMS symptoms, particularly pain.

*“not able to do things I used to do. I am struggling with housework and swimming, undo lids off or jars and things without trouble. I don’t have the STRENGTH. ... I WAS (with insurance company). But I couldn’t keep it going because I lost my job.” (P2)*

*“well down. I can’t drive my old cars. That was a H-U-G-E part of my leisure time. I can’t BUY things from the museum like I USED TO because I am spending so much on doctors’ bills and medications, there’s big pocket hole there.” (P7)*

*“involved with ACC, another about quality of life. It’s loss of control. I have to hand control of what’s happening with or to my body to medical professionals.” (P4)*

*"If I do things, it's because I need to not because I want to. My quality of life has changed. My enjoyment of things that I used to do has changed."* (P4)

*"Yeah, pain and fatigue and stuff changes A LOT."* (P3)

*"Yeah. But then I don't think about it. It's part of life so I don't worry about it."* (P6)

Pain and discomfort were found to significantly influence perceptions of sufferers' QOL and physical wellbeing reported in a wide range of diseases/disorders in Britain (Skevington, 1998). Skevington found that QOL, regarding pain and discomfort, showed correlations between negative feelings and six other aspects: availability of social care, mobility, daily activities, positive mood, sleep, and medication dependence. Together, these seven factors explained a substantial proportion of quality of life in pain and discomfort, and represented criteria against which the success of pain treatments could be evaluated.

In a comparative study by Burckhardt et al. (1993) on QOL of female FMS patients compared to women with other chronic illnesses, results indicated that FMS patients' QOL was adversely influenced to an extent that was not formerly acknowledged. However, the duration of such illness was not found to relate to the QOL scores among the participants.

Due to the decline of patients' health and psychological status and physical mobility, the number and level of daily activities reduces. Their inability to achieve personal objectives, constrained socialisation and relationships, reduced activity levels, as well as insufficient support from family and friends are typical hardships for FMS patients (Hanricksson, 1995, cited in Affleck et al., 1998). Patients' efforts to cope with these burdens typically include adjusting daily routines (that is, pacing activities to avoid the worsening of pain and fatigue), rearranging daily priorities, and pursuing new goals and interests. By having a continuous, chronic illness such as FMS, people may learn to be helpless and dependent through decreasing the extent of physical and social daily activities and may seek more help from others than necessary (Henriksson & Bengtsson, 1990).

## SUMMARY

FMS touches every aspect of the patient's life, which brings about a wide range of changes and frustrations and, therefore, reduces sufferers' quality of life. Consequences reported by most FMS patients range from chronic pain, loss of and physical fitness and ability, psychological distress, psychosocial limitations and modifications, impaired lifestyle functioning, reduced occupational capacity and competence to possible unemployment or disability. FMS patients' satisfaction with medical health services also plays a part in intervening with patients' conditions and is predictive of treatment effectiveness.

## CHAPTER TEN

# DISCUSSION

The final chapter presents a discussion of the findings of this study, together with the limitations of these findings and implications for future researchers, clinicians, FMS patients' and their significant others. The first section of the chapter overviews the main findings presented in relation to the investigation objectives. The second part describes some limitations of the present study, with the third section making future recommendations.

In this study, participants were regarded as subject matter experts (SME's), who were invited to share their experiences of FMS with the researcher. Through a process of semi-structured in-depth interviews, the researcher explored how participants perceived, assessed and understood themselves in relation to their FMS condition. Of particular interest was the perceived aetiology, symptoms, intervening conditions, coping strategies, and consequences of FMS. Although FMS has been investigated in many clinical studies within a variety of paradigms, the present investigation was unique in its use of individual self-reports and grounded theory analysis of FMS experience. This was done in the hope of greater sensitivity to subtle differences in data when compared with group reports, or the reductionist approach of quantitative research. As a result of this, findings concurred with, contradicted, and expanded on the existing literature.

As a grounded theory investigation the paramount objective was to identify a core factor that captured participants FMS experience. Because it meet the criterion for the core category, *living with Chronic pain* emerged as the basic social process (BSP) underlying the FMS experience from the patient's perspective. In fact living with chronic pain was continuously and pervasively described throughout all aspects of the FMS experience across all participants. It impacted in a cyclic way on the occurrence and severity and type of other FMS symptoms; intervening conditions; consequences; coping strategy evolution, adoption, cessation and effectiveness of strategies; treatment outcomes; and lifestyle adjustments. For instance, living with pain related to participants' activity levels, arousal, sleep disturbance, energy levels, fatigue, socialisation, mood, emotion, and cognitive performance. This concurs with the work of Bennett & Jacobson (1994), who found that chronic widespread musculoskeletal pain was the most critical

factor identified by the majority of FMS sufferers, and Jacobson's (1994) report that pain is the most disturbing and persistent aspect of the FMS experience.

## **DISCUSSION OF THE PRESENT FINDINGS**

### **Aetiology of FMS**

Patient perceptions regarding the cause of their FMS concurred with earlier research that aetiology is multifactorial (Sarnoch et al, 1997). In addition to this, patients identified both specific and non-specific categories of aetiologies for FMS. These categories paralleled the reactive and idiopathic division of aetiology proposed by Turk et al (1996), although participants in this study consistently described combinations of these aetiologies in contrast to earlier research and all participants from this study described a reactive FMS onset. Another salient aetiology emerging from the present investigation is the description of possible hereditary onset. Participants reported recurrent similar symptoms such as diffuse musculoskeletal pain and tenderness across family members. However, reports of similar symptoms between family members were based solely on participants' reports of their relatives condition. Despite this, a hereditary onset supports the suggestion of Block, (1993), Ediger (1991), Henriksson & Bengtsson, (1990), and Henriksson (1994) has implication for identifying a susceptible population.

Other, more peripheral factors described as causally linked to the development of FMS include non-restorative and abnormal sleep pattern, neurotransmitter deficiencies, and psychological disturbance. Childhood and adult trauma, and adult relationships were believed to either directly or indirectly contribute to the development of FMS. In fact, many participants described themselves through Type A personality characteristics, which emerged as both a cause of FMS and an aggravating factor of symptom severity. Moreover, those who described a Type A personality also described a hereditary predisposition to FMS. Although preliminary, this link appears to reinforce Friedman et al's (1987) proposition that Type A personality are a *generic* FMS prone groups.

Finally, data from this research provided additional support for the suggestion that trauma (PTSD) during childhood aggravates the development and symptom severity of FMS. Amir et al.'s (1997) study found that PTSD was strongly associated with FMS, and that those with both disorders exhibited more diffuse pain, increased pain sensitivity, more nonarticular tenderness, higher functional impairment, more psychiatric symptoms

than those with just FMS or PTSD alone. Although not diagnosed with PTSD, participants who described traumatic life events had more severe FMS symptoms and a belief that their FMS was caused by trauma.

This diversity of potential onsets and a lack of agreement with and between the literature demonstrate the inadequacy of existing classifications as simply either idiopathic or reactive. What evidence there is for the aetiology of FMS is unsubstantiated, lacking in explanation, and inconsistent between different FMS populations. Despite the ambiguities of the clinical research, all participants in this study clearly identified causal factor(s) for their FMS, by describing combinations of both types of onsets.

### **Susceptible Populations**

Eight of the nine participants in this study were woman and it is possible that this may indicate a susceptible population, rather than just a artefact of the phenomenon of women volunteering more for research participants than men. This possibility is supported by Wolf (1990) and Yunus (1988), who found that FMS was most prevalent in physically and psychologically susceptible woman between the age of 20 and 60 years old. Moreover, the Copenhagen Declaration (1992) specified that women are affected some 12 to 20 times more often than men. Finally, the gender ratio in the present investigation is consistent with the gender ratio of FMS susceptibility presented by the Copenhagen Declaration (1992). However, subsequent work indicates an increasing prevalence of FMS in males and all age groups. This research also suggests that FMS begins at an earlier age than first suspected and might indicate that children are another at-risk subgroup. Childhood indications were certainly described by subjects as manifested by headaches, "growing pains", and often, the previously mentioned symptoms (Block, 1993).

### **FMS Symptoms**

Participants discussed a complex range of physical and psychological FMS symptoms, which were found to interrelated in a cyclical manner with reciprocal effects originating from chronic pain (Amir et al., 1997; Kurtz et al., 1998). Initially, chronic pain assumed a fairly dominant role in the symptoms of FMS which was reflected in the terminology used by FMS patients to describe it. Terminology used was both affective and sensory,

paralleling Baumstark et al.'s (1993) study. Participants described pain in a variety of settings, pain intensity, and lowered pain threshold in a manner documented in the literature (Bennett, & Jacobsen, 1994; Lautenbacher et al., 1994; Simms et al., 1988). Pain tended to be generalised musculoskeletal, or localised to different anatomical structures and surfaces that shifted and fluctuated in severity in response to context, between sites and participants. These sites could be identified as broad physical systems of the body including the skeletal system, visceral system, striated and smooth muscles, respiratory system, and central and peripheral nerve systems. Within these categories localised pain occurred at articular surface and associated musculoskeletal sites (i.e. in the neck, back, shoulders, wrists, knees). This type of pain tended to promote the development of migraines and headaches, and facial pain such as pain in the temporomandibular joint (Pellagrino, 1990). Besides these carry-over effects pain was also associated with a decline in cognitive performance, including impaired short term memory (STM), decreased concentration span, confusion, decreased mobility, and a decline in immune system and circulatory systems function (Bennet, 1989; Wallace, 1997).

Other physical symptoms included reports of "paresthesia", or prickling or burning sensation, particularly in the extremities (FMAGW, 1995), including numbness and tingling in their hands, arms, feet, legs, and face. There were also reports of disturbances in digestive function such as abdominal pain, bloating, constipation, and diarrhoea. As a whole, such symptoms are known as irritable bowel syndrome (IBS) (Ediger, 1991). Finally, as in the literature, participants here reported a higher than average tendency to allergies than normal population (Ediger, 1991). Allergies were the only symptoms mentioned by FMS participants that had no association with pain or any other FMS symptoms.

Abnormal sleep patterns and sleep disturbance were reported to both cause FMS, and aggravate other FMS symptoms including reduced energy reserve, fatigue, pain, impaired psychological and cognitive wellbeing. These findings were in agreement with Haythornthwaite et al. (1991) and Henriksson (1994) who reports that poor sleep can potentially trigger FMS symptoms, including moderating pain severity, which feeds back to disturb sleep patterns. The effects of sleep disturbance may have partly caused participants' constant state of fatigue, which in turn inhibited their physical endurance (Bennett, 1989) and resistance to chronic pain. In fact, most participants regarded fatigue as one of the dominant symptoms of FMS, frequently as severe as chronic pain. This data

is similar to earlier work conducted by Hanricksson et al. (1992) where FMS participants considered fatigue to dominate over chronic pain as the most disturbing FMS symptom. The mechanisms underlying the cycle of poor sleep, reduced energy, lowered mood, fatigue, and increased pain tended to support Wallace's (1997) hypothesis that sleep disturbance evolved from poor sleep habits, and generalised weakness in skeletal muscle. Individuals' fatigue varies in terms of severity, timing distress, and levels of interference with daily activities. Psychological variables, such as depression and anxiety, can also influence patients' fatigue severity (Gaston-Johansson et al., 1990). Also associated with fatigue were consistent reports of a reciprocal relationship between chronic pain, psychological disturbance, and energy reserves, sleep disturbances. This finding is similar to Affleck et al. (1992) Stone et al. (1994), and Totterdell et al. (1994) findings, where participants reported that pain severity, fatigue, and sleep disturbances were predictive of their daily emotional wellbeing.

In addition to the physical symptoms of FMS, a number of well-defined psychological symptoms including psychological distress, anxiety, depression, and mood swings were reported by participants. Psychological distress evolved out of the pressures to cope with FMS, and public misperceptions about the legitimacy of the disorder as proposed by Gaston-Johansson et al. (1990). Depression and anxiety tended to lead to a loss in life quality, loss of independence, loss of health, increased fatigue and physical impairment (Wallace, 1997), employment, and relationship difficulties, that aggravated other FMS symptoms. Participants in the present study described both anxiety and depression as salient symptoms of the FMS experience, in line with previous literature (Boissevain & McCain, 1991; Hawley & Wolfe, 1991; Hudson et al., 1985; Goldenberg, 1986; Krag et al., 1994). Mood swings emerged as the dominant affective response to FMS symptoms and pain severity, although prescriptive drugs taken by participants, such as Prozac, are known to moderate mood. Similar to Vendrig & Lousberg (1997) mood and pain intensity was found to be worse during the morning with improvements during the afternoon. Mood was also associated with sleep deprivation, possibly because sleep deprivation lead to loss of opportunity to generate serotonin, a neurotransmitter for regulating emotion and sleep patterns (Chaplin, 1985).

In summary, symptoms for the present participants over-lapped with the findings of previous studies. Both chronic pain and fatigue were among the dominant physical symptoms, with sleep disturbance, fatigue, and reduced energy been less important, although linked in a cyclic manner. Irritable bowel syndrome, paresthesia, and allergies

were also described by some participants. Psychological and effective symptoms included depression, and anxiety, and mood swings, which evolved from the effects of physical symptoms, pressures to cope, and shifts in lifestyle imposed by the FMS condition.

### **Intervening Conditions**

In addition to the variable onsets and symptoms of FMS, there are a number of intervening conditions that emerged to inhibit or enhance the severity of FMS symptoms. These were coded as finance, person-orientation, medical-oriented, information & awareness, environmental, social support factors, and social misperceptions. Within these broad groups of intervening conditions sub-factors such as climatic conditions, and activity levels/type (i.e. working in prolonged isometric positions) regulated the severity of FMS symptoms as found in earlier studies (Kalyan-Raman et al., 1984; Hagglund et al., 1994; Wanlonis, et al., 1994). Other variables such as job dissatisfaction, ergonomic arrangements, public and professional attitudes, practitioners' FMS knowledge have been described as mediators of an FMS epidemic (White, et al., 1997). Finally, stress, infection, and over-exertion caused symptoms to fluctuate in severity.

In the present study, the financial intervening conditions comprised the level of compensatory assistance provided by government departments, including ACC and Work & Income New Zealand. The present population indicated that financial assistance governed by entitlement criterion determined by public policy of these departments did not accommodate needs of those with FMS. Lack of assistance lead to a decline in participant health via a lack of acknowledgement of the legitimacy of the disorder, and because participants could not afford prescriptive medications. Whether directly or indirectly through the medical intervening condition, the financial intervening condition seemed to improve or reduce individuals' physical and psychological wellbeing.

Most participants in this study evidenced a similar personality to that known as Type A under the category of person-oriented interventions. All participants explicitly identified themselves as over-achievers. Although not explicitly stated by every participant during interviews, some participants concluded that their personality characteristics served as another causal condition of FMS. Another personality type, the introvert, appeared to promote a tendency for internalisation of negative feelings, which precluded some participants from receiving adequate social support.

Medical intervening conditions produced immediate physical and psychological consequences. Most patients reported an association between sub-standard medical assistance, including poor practitioner attitudes and a lack of provision of medical information, mis-diagnosis and inappropriate treatment, to have aggravated their physical and psychological FMS symptoms. Some participants believed that inappropriate prescription and manipulative treatments acted as a catalyst, which exacerbated their FMS symptoms.

Information and awareness was classified into active and limited information. Active information searches directly and positively influenced participants' physical and psychological condition, with the opposite outcome for limited information search. It appears that knowledge of the condition 'empowered' participants to search for solutions to the symptoms of their condition.

Within the environmental category climatic conditions, including cold, dampness, and rain mediated the severity of these participants' FMS conditions, including pain intensity and cognitive functioning. This heightened sensitivity to environmental stimuli has received wide support in the literature (Bennett & Jacobsen, 1994, Copenhagen Declaration, 1992, Hagglund et al., 1994, Kalyan-Raman et al., 1984, Lautenbacher et al., 1994, Simms et al., 1988, Wanlonis et al., 1994, & White et al., 1997).

In the present study, all participants discussed having specific social support needs, such as understanding, a need to modify and regulate their activities (i.e. in employment), and a need for others to adjust their expectations of the participant with FMS. They also outlined specific concrete needs such as help in getting around, help with housework, and help with their treatment interventions. The provision of needed social support was associated with an improvement in subjects' FMS symptoms.

Although the literature indicates that society is beginning to take notice of FMS, it is still largely ignored or disregarded by many, falling into the category of "unseen" syndromes (Yunus, 1994). Regardless of the empirical evidence of impaired motor functioning (Henriksson et al., 1992) and psychosocial difficulties (Raymond & Bergland, 1994), patients with FMS have been frequently incriminated as "advantage takers". Misconceptions of their use of unentitled privileges include over-utilising of health care and financial support, taking excessive sick leave, limiting their activities in the workplace and at home. These misconceptions resulted in many FMS sufferers feeling misunderstood with an associated reduction in their wellbeing. Similar to Raymond & Bergland's (1994) findings, this study shows that a lack of validation for participants

FMS condition from their families, friends, employers, colleagues and health-care professionals, intensified psychological stress, lowered self-esteem, negative feelings, despair, and alienation. The need for validation of their disorder from associates, groups and government institutions was important for participants, who often described a decline not only in their health, but also in their belief in the conditions. This acted to intensify symptoms through the engagement in inappropriate activities. Part of the validation process came from a proper diagnosis that helped patients to label and identify with their condition in a manner paralleling Kelley & Clifford's (1997) research.

### **Coping Strategies**

Six general categories of active coping strategies were found in this study, including cognitive coping strategies, behavioural coping strategies, cognitive-behavioural coping strategies, psychological interventions, family and social support, and perceptions of emotional states, with most concurring with the existing literature. Within each of these categories sub-categories of coping strategies were found. For instance, cognitive coping strategies included the sub-categories of cognitive resolution, non-self-defeatist attitude, and positive deferral. Across all of these categories was a pattern whereby those with increased coping experience utilised a more sophisticated repertoire of successful coping strategies that lead to less severe pain and a reduction in other FMS symptoms. Moreover, with increased coping strategy experience, participants became more adapt at adjusting and fine tuning coping mechanisms dependent of the type, severity, site, and context of pain and other FMS symptoms. For instance, coping in social settings was a balance between maximising effectiveness and minimising the visibility of the coping strategy in relation to wanting to appear normal. Finally, those with more experience in coping with FMS learnt to gradually adjusted to pain through a process of desensitisation and habituation. In part these changes could be attributed to the development of an effective repertoire of individualised of coping strategies.

In relation to cognitive coping participants' level self-efficacy in pain management became the key psychological factor, which enabled participants to cognitively resolve their FMS conditions and reduce pain symptoms. In more general terms, participants 'believed' or 'learnt to believe' in their ability to rationalise pain to a controllable level. It was this process that then allowed participants a form of cognitive relief from pain and other FMS symptoms. More over, cognitive resolution altered as

participants habituated to pain, allowing participants to successfully utilise strategies like positive deferral. Other strategies like non-self-defeatist attitude, and strategies altering the pain sensation addressed different aspects of pain appraisal. These strategies allowed participants to feel that they had the ability to tolerate and accept pain in order to minimise disruptions to their lifestyle.

Behavioural coping strategies helped to elevate FMS symptoms. These included behavioural adjustment strategies such as ergonomic relief, frequent movement, stopping and resting, exercise, continuation with current activity, self-imposed lifestyle limits, and self-imposed intimacy limitation. Participants attempted to adjust their behaviour and maintain a balance between continuing to engage in daily activities, while tolerating a degree of pain induced through activity and discontinuing activities when pain severity became unbearable. Participants typically assessed their physical limitations through trial and error as part of the experience-and-learning process, beginning relatively soon after the onset of their conditions.

Participants reported using cognitive-behavioural distractions through the course of their FMS, which helped to divert attention from pain. The use of these strategies tended to be influenced by situational contexts, particularly the use of distraction technique(s). For instance, in social settings, participants described using cognitive-behavioural strategies such as distraction involving significant others, which provided participants with a sense of social support and a buffer from pain and other FMS symptoms.

A commonly used psychological strategy relied on the use of intentional denial and avoidance of FMS symptoms. In this study findings contradicted earlier work like that of McCracken's (1998), who found avoidance strategies to be unproductive for coping with chronic pain. Several of the present participants considered them effective throughout their FMS experiences. Another salient psychological intervention designed to aid in the management of chronic pain, disability, and emotional and psychological distress fitted well with categories from the literature that identified directive and non-directive treatments (Erickson, 1966, cited in Neumann et al., 1997). Directive interventions used in this population paralleled previous findings by centring on the rational, self-consciousness strategies that helped to prolong and increase pain tolerance. Non-directive interventions, such as hypnosis, function without conscious cognitive operation and were rarely used by participants in this study. Additionally, various motivation techniques were used by participants to manage pain, including relaxation,

imagery, goal setting, positive self-talk, and behavioural therapy (Bloomfield et al., 1992). Generally, data from this study supports Bloomfield et al.'s (1992) classification of psychological intervention, although a number of motivation techniques reported in the literature were not widely used by the present participants. Those that were used were used by some and not others. Despite the low prevalence of use, those who did rely on motivation techniques commented on a high degree of effectiveness. Finally, social support was often used by participants in conjunction with other coping strategies, like cognitive-behavioural strategies.

In summary, present findings support the suggestion of the adoption and development of spontaneous coping strategies. Moreover, the implications from the literature are that patients' concepts of illness, the meaning ascribed to the pain in relation to the significance of the illness, and time since onset work together to regulate the choice and use coping strategies.

### **Choice & Evolution of Coping Strategy**

The changing process of living with chronic pain that was generated from the participants' data, is consistent with Suls & Fletcher's (1985) concept that the process of coping mechanisms changes over time. Data also supported Horn & Munafò's (1997) individual and situation specific theory, which suggests that coping behaviour is influenced by individuals' personal and situation resources. Changes in the use of coping strategies interacted with changes in appraisals and contexts and the perceived consequences. The severity of FMS symptoms (pain in particular) in conjunction with other contexts (such as situational context and the length of time since onset) were predictive of the use of a range of coping strategies. However, the emergent theory developed from the participants' data indicated that the severity of pain was the primary moderator of participants' choice of coping strategies on the basis of experience and effectiveness. This supports Turner et al. (1987) notion that coping with chronic pain should be viewed as a process, with different coping strategies used at different phases. As proposed by Silver & Wortman (1980, cited in Homes & Stevenson, 1990), no one coping strategy is superior to another. Each coping strategy generated positive outcomes under different circumstances.

### **Treatment Regimes**

Given the severity of FMS symptoms, treatment regimes assumed a quite dominant feature of participants' FMS experience. This was reflected in their motivation and attempts to minimise their pain. Given that no singular universally effective cure exists for FMS, participants tended to rely on a combination of pharmacological, psychological, and physical therapies directed at symptom relief, pain management, and the maintenance of physical condition as do other chronic pain sufferers (Mason et al., 1998). Similar to findings of Mason et al. (1998) a multi-modal approach to treatment was described as most effective, specifically where a combination of cognitive-behavioural techniques were used in conjunction with physical therapy and pain medication reduction. Similar to Mason et al (1998) the multi-modal approach to treatment was found to result in positive immediate and long-term effects on participants' psychological wellbeing as well as lowered pain perceptions, temporary alleviation of pain, improved mobility, and reduced muscle tightness (Ediger, 1991), and an improved quality of life and personal wellbeing (Metcalf, 1990, cited in Feine & Lund, 1997). For instance, exercise lowered pain intensity, the number of tender points, improved physical endurance and general mood. Bennett et al. (1996) also found that patients' condition improved in the long run through the provision of accurate diagnosis, cognitive-behavioural interventions, and aerobic physiotherapy. Feine & Lund (1997) found a tendency towards short-term improvements in efficacy despite the therapy adopted. Patients became less anxious towards the future and paid less attention to pain when they receive both physical therapy and better information.

The ultimate consequences of FMS for everyday activities such as work, family life, and leisure depend not only on sufferers' conditions and pain, but on the individual and on each person's unique set of earlier experiences, values, and environmental conditions. A treatment programme should not only aim at diminishing pain and sleep disturbances but also rearrange daily activity patterns in such a way that patients can cope successfully despite their symptoms. A careful assessment of the patient's present life situation and previous experience will give valuable information for understanding each patient's ability to manage his or her situation and provide a realistic background for preventive or rehabilitative assessments. Given the scope and cost of FMS as well as the personal suffering, there is a need for low-cost, accessible and effective interventions that will help patients find ways to better manage this difficult issue. One example for treatment programme is an accessible, community-based approach.

## **Consequences**

Six general categories of consequences emerged from the data including, illness impact on health & related matters, on emotions, on social relations, on employment, on relations with health care services, and general impact of living with chronic pain. Consequences reported by most FMS patients included chronic pain, loss of physical fitness and ability, psychological distress – anxiety and depression, psychosocial limitations, impaired lifestyle functioning, impaired occupational capacity, and social exclusion. Consequences of FMS fluctuated daily in response to intervening conditions, context, and coping strategy use.

## **Some New Findings**

Six previous unreported phenomenon emerged from the data as a consequence of the research design. Firstly, a common reaction from patients' GPs to ACC policy was a deliberate mis-diagnosis of their FMS as an ACC-recognised chronic pain condition. This strategy appeared to have been adopted by GPs to circumvent ACC's Intentional denial of FMS claims. Secondly, several participants reported how the experience of FMS symptoms and pain had changed their personality in general. Those who exhibited a Type A personality described a gradual mellowing in their excessive achievement behaviour as a result of physical de-conditioning since the onset of their FMS. Thirdly, the evolution, adoption and abandonment of coping strategies, and the expression of pain, behaviour, sociability, mood, and activity levels were influenced by an interaction between pain severity, time since onset of FMS, context, and the level of success or failure of coping strategies. Each participant described a variety of coping strategies which they currently preferred and which were either applied in combination or singly, dependent on the context. Fourthly, consistent with chronic pain patients' studies, participants reported using a broad range of other health services such as physicians and counselling. Moreover, in support of Keefe et al.'s (1992) proposition, several participants reported the use of journal-keeping on the prognosis and effectiveness of various coping strategies as a guide for themselves and their medical practitioners' to future treatment regimes. Fifthly, the youngest participant regarded the FMS experience as educational and maturing catalyst that made her more sensitive and understanding of herself and other people, particularly those with personal problems. Finally, an association between the aetiology and the impacts of FMS emerged whereby individual with combined reactive and

idiopathic aetiologies exhibited less illness worries. It could be that the gradual development of the condition that goes with an idiopathic onset allows patients a period of time to adapt to their condition, unlike the reactive aetiology, where FMS onset is more rapid. This proposition, although untested, seems reasonable given that participants with a reactive onset described more social, economic, pain severity (Turk et al, 1996), affective distress, lower activity, and greater functional impairment than idiopathic (Greenfield et al, 1992), combined, or those with multifactorial aetiology.

### **LIMITATIONS OF THE PRESENT STUDY**

The degree to which participants' self-reports coincide with the perceptions of their significant others may differ. Consequently, data regarding significant others perceptions obtained from research participants may not always be entirely accurate given the data's secondary nature. Past research has proposed that there is not always a positive correlation between perceived social support and objective measures of social support (Lazarus & Folkman, 1984). It is possible that participants' perception of support in this study would differ from the support or support reported by significant others. Using only participants' self-reports meant that information from outside observers, such as friends and family, was not obtained.

Participants' retrospective reports of remembered events precluded access to experiences as they occurred. Participants' memories may be supplemented and transformed as new knowledge, information, or stimulus about the same or similar experiences are encountered, that act to modify the original memories. For instance, participants' retrospective descriptions of pain may not be an accurate representation of their experiences of pain as it is experienced.

Diagnostic problems mean that there are few adults diagnosed with FMS syndrome and this resulted in the sample size being limited to eight participants. This small sample size makes it both difficult to generalise the emergent theory across wider population of FMS sufferers, and brings into the question the reliability of the emergent model. Despite these problems, the research provides subsequent investigators with a suitable emergent framework for testing and further theory development.

Although triangulation was conducted in terms of comparing data among participants, it was not when it came to the use of combined multiple qualitative and quantitative data

types (Leininger, 1992). The exclusive reliance on participants' self-reports of their FMS experience, with no other data being collected brings into questions the reliability and validity of the findings where there was a failure to cross-reference data and methods. A lack of time to utilise multiple methodologies in the present investigation meant that data source coherence could not be checked against the present findings (Leininger, 1992; Marshall & Rossman, 1995). Furthermore, the sole reliance on self-report data does not lend itself to cross validation of the emergent theory that would come from using multiple qualitative and quantitative data types.

The lack of follow-up interviews with both initial subjects and new participants precluded the researcher from addressing the issue of triangulation and generalisation of the emergent model to other diagnosed sufferers of FMS. Instead, the derived conceptual model is limited to the initial study group, validation of the model in a follow-up study would support generalisation of the model to other groups.

The quality of the emergent theory, data analysis, level of abstraction, and results derived using a grounded theory approach can be endangered by the researcher's training, experience, self-confidence, personal feelings, motives and tolerance for ambiguity. Given that the investigation was conducted with the guidance and scrutiny of qualified supervisors, it was felt that such influences were minimised.

Finally, restrictions are imposed on how much of a grounded theory approach one can adopt in conducting research, particularly a master's thesis with its limited tenure. Likewise, there are restrictions on how theoretically pure one can be using grounded theory in a master's project. With this in mind there is always more data that can be found, another angle that can be chosen to look at, more ways/scopes of going about doing it.

## **IMPLICATIONS FOR FUTURE RESEARCH**

Given that this investigation was conducted using one-to-one interviews and Strauss & Corban's (1990) paradigm model as a source of insight into the FMS condition, several new perspectives emerged. Consequently, the present investigation has several important implications for future research efforts.

Firstly, the emergence of living with pain as the BSP in a paradigm model for FMS lends itself as a source for generating subsequent research into the mechanisms of

pain. Ultimately, understanding of these pain mechanisms can lead to better diagnostic and treatment regimes for medial practitioners and perhaps better medical support for those living with chronic pain.

Other important findings included the emergence of a challenge to the traditional aetiological classification of FMS into reactive and idiopathic categories. With new findings indicating combined idiopathic and reactive aetiologies as well as multi-factorial causes, including familial and possibly hereditary factors, it is crucial that further study is conducted to clarify the causal mechanisms of FMS to promote improvements in diagnostic criteria. Similarly, the prognosis and symptoms of FMS still lack explanation as highlighted by the discovery in this study of a cyclical association between pain, fatigue, and sleep disturbance and other physical and psychological FMS symptoms which interact to aggravate one another. In addition, the emergence of intervening conditions that appear to moderate the severity of FMS symptoms, including the influence of medical and financial factors, both require further exploration.

A pattern of susceptibility with woman predominantly suffering from FMS may be an artefact of this particularly research, or an indication that FMS is largely an experience of women. Given the uncertainty it is clear that follow-up research is needed to verify this situation and account for differences in FMS between different types of populations.

Given that the present study was conducted using a cross-sectional retrospective interview design with a small sample, follow-up work should be done using longitudinal designs and bigger sample populations. Longitudinal designs would more accurately capture the evolution of the FMS experience in terms of changes in patients beliefs about aetiology, symptoms, prognosis, coping mechanisms, intervening conditions and consequences. This style of research would be particularly valuable given the chronological changes that appear to occur since the onset of the FMS condition. From this, theories on FMS can be refined, verified, and extended.

Journal-keeping might prove useful as a means of data collection to ensure greater accuracy in self-report data. Having participants transcribe their own thoughts and beliefs about various aspects of their FMS condition, might eliminate some of the limitations of retrospective designs. The actual process of diary keeping itself may also help patients to better understanding and therefore cope with their condition. Other designs include a focus of group approach, which might also give patient's better insight into their condition. As suggested by Kelley & Clifford (1997), the in-group discussion

enables participants the opportunity to re-examine and re-feature their lives, to not engage in emphasising the incidences of helplessness, and to utilise their own resources.

Furthermore, observation technique has important implications for post-treatment planning and for future research (Mason et al., 1998). Relapse prevention should be emphasised and efforts should be made to encourage patients to continue to exercise together and participate in regular support groups. Additionally, follow-up studies should be designed to evaluate FMS patients' pain intensity and physical and emotional functioning with the minimum of one to two years after completion of treatment intervention. These studies should include assessments to evaluate personal adherence to the programme components.

A paradigm model reliant on patients' self-reports has proven fruitful for generating theory of the FMS phenomenon. However, without follow-up qualitative and quantitative investigation to test the model, little advancement beyond speculative mechanisms can be made. The present study provides an untested, but conceptually fresh theory on the aetiology and effects of FMS. Quantitative research could supplement this research by demonstrating the model's degree of generalisation and may also contribute to validating the shape, structure, links, and factors of the emergent model. However, both qualitative and quantitative approaches would assist in better clinical definition and diagnostic criterion for FMS. This would have a carry over effect for both practitioners through more accurate FMS diagnosis, and for sufferers in terms of been warned earlier on how to deal with their condition.

The use of various prescriptive medications and coping strategies needs further research given the individual variation in success rate reported in this study. This is particularly pertinent when considering the numerous published studies on the aetiology and diagnostic criteria of FMS, with only a few investigations treatment outcomes. The strength of the present study lies in its provision of an initial framework in terms of coping strategy success, evolution of use, and cessation in use.

## **IMPLICATIONS FOR MEDICAL PRACTITIONERS & SIGNIFICANT OTHERS**

There is an indication that both medical practitioners and significant others play an important role in mediating the severity of FMS symptoms. Findings indicate that practitioners need to be more sensitive to their patients' perceptions of their doctors' attitude. It is recommended that practitioners learn to regulate their verbal and non-verbal signals and actions given patients' sensitivity to these factors.

In diagnosis of FMS, practitioners need to develop a broader interpretative approach by taking note of the unique contextual factors for each individual case. Medical practitioners need to nurture awareness of the interplay between pain prognosis, symptom severity, and various intervening factors. In developing this awareness, medical practitioners should more closely collaborate with their patients as subject matter experts (SME's), particularly long-term sufferers. During the design, implementation, and maintenance of treatment regimes, medical practitioners should consult with patients, other practitioners, and significant others regarding the success and potential of various coping strategies. Obviously, a co-operative approach to treatment would require careful consideration of ethical and privacy issues although insight from the present investigation highlights the need for a global perspective on the patient's condition. Patients and significant others' consultation may guide the medical practitioner to the various intervening and contextual factors that influence symptom severity and or coping strategy success, given that these outcomes cannot be viewed in isolation. For instance, the current severity and constancy of the patients' pain, time since onset, and situational influences, such as employment, living arrangements, social activity, and physical activity should be considered. When considering coping strategies, medical practitioners should not only consider prescribed strategies, but also those adopted and or recommended to their patients by others. Many of these non-prescriptive coping strategies may be 'alternative' or non-institutionalised in nature with little or no clinical support. Despite this, medical practitioners should be more open to the possibility that these types of self-prescribed treatments are effective. Moreover, medical practitioners need to identify the relationship between various coping strategies and patient daily activity and context. Through this process, medical practitioners would be better placed to refine and manage their FMS patients' treatment regimes, and reduce reliance on often-expensive non-effective prescriptive medications. Beyond medication and coping

mechanisms, medical practitioners should encouraged FMS patients to regulate their activity in a responsible way, resting when necessary, and monitoring their exertion and symptom response. Apart from a consultative role, significant others including family, friends, and spouse should be careful to provide support to FMS sufferers in a manner that suits the patient.

Another important issue is a need to explore patients' fear regarding their conditions and pain. Findings seem to indicate that lack of awareness of FMS condition leads most patients to a fear and anxiety response arising from the unknown and how to cope with it. It is crucial that medical practitioners furnish their patients with current and accurate information about their condition, listening to their concerns, and providing honest answers to their questions. However, many of the FMS patients interviewed had not had this courtesy paid to them. Participants' moving on from fear of their condition and continuous pain was facilitated both by their experiential learning of coping strategies and increased knowledge which arose from both their own expertise and from active and passive information-seeking. At a later stage in the process, participants became more interested in how to live with their condition, pain, and how to get on with their lives. It should be noted again that stages could be re-visited in relation to current contexts. Therefore, being aware of individual FMS patients' needs is important.

Medical practitioners need to be aware that FMS patients who experience chronic pain subjectively habituate to pain. They still feel pain, but it bothers them less. This has implications for allowing patients to continue and remain involved in activities. This information also has relevance in instances where level of disease activity is assessed in relation to the severity of pain reported by FMS patients. Furthermore, it seems likely that FMS patients' severity and frequency of pain may have been underestimated by medical practitioners and researchers because of patients' capacity to subjectively habituate to pain and to initiate coping strategies that have been found to be adaptive.

## REFERENCES

- Aaron, L. A., Bradley, L. A., Alarcon, G. S., Triana-Alexander, M., Alexander, R. W., Martin, M. Y., & Alberts, K. R. (1997). Perceived physical and emotional trauma as precipitating events in FMS: associations with health care seeking and disability status but not pain severity. *Arthritis & Rheumatism*, *40*(3), 453-460.
- Affleck, G., Tennen, H., Urrows, S., & Higgins, P. (1992). Neuroticism and the pain-mood relation in rheumatoid arthritis: Insights from a prospective daily study. *Journal of Consulting and Clinical Psychology*, *60*, 119-126.
- Affleck, G., Tennen, H., Urrows, S., Higgins, P., Abeles, M., Hall, C., Karoly, P., & Newton, C. (1998). FMS and women's pursuit of personal goals: A daily process analysis. *Health Psychology*, *17*(1), 40-47.
- Ahles, T., Yunus, M., Riley, S., Bradley, J., & Masi, A. (1984). Psychological factors associated with primary fibromyalgia syndrome. *Arthritis & Rheumatism*, *27*, 1101-1106.
- Almay, B. G. (1987). Clinical characteristics of patients with idiopathic pain syndromes. Depressive symptomatology and patient pain drawings. *Pain*, *29*, 335-346.
- Amir, M., Kaplan, Z., Neumann, L., Sharabani, R., Shani, N., & Buskila, D. (1997). Posttraumatic stress disorder, tenderness, and FMS. *Journal of Psychosomatic Research*, *42*(6), 607-613.
- Anells, M. (1996). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, *6*(3), 379-393.
- Arntz, A., Dreessen, L., & Merckelbach, H. (1991). Attention, not anxiety, influences pain. *Behaviour Research and Therapy*, *29*, 41-50.
- Astin, M., Lawton, D., & Hirst, M. (1996). The prevalence of pain in a disabled population. *Social Science & Medicine*, *42*(11), 1457-1464.
- Baker, C. & Stern, P. N. (1993). Finding meaning in chronic illness as the key to self-care. *Canadian Journal of Nursing Research*, *25*(2), 23-36.
- Baker, C., Wuest, J., & Stern, P. N. (1992). Method slurring: the grounded theory/phenomenology example. *Journal of Advanced Nursing*, *17*, 1355-1360.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioural change. *Psychological Review*, *84*(2), 191-215.
- Basler, H. D. & Rehfisch, H. P. (1990). Follow-up results of a cognitive-behavioral treatment for chronic pain in a primary care setting. *Psychology and Health*, *4*, 293-304.
- Baumstark, K. E., Buckelew, S. P., Sher, K. J., Beck, N., Buescher, K. L., Hewett, J., & Crews, T. M. (1993). Pain behaviour predictors among FMS patients. *Pain*, *55*, 339-346.

- Becker, P. H. (1993). Common pitfalls in published grounded theory research. *Qualitative Health Research*, 3(2), 254-260.
- Becker, N., Thomsen, A. B., Olsen, A. K., Sjogren, P., Bech, P., & Eriksen, J. (1997). Pain epidemiology and health related quality of life in chronic non-malignant pain patients referred to a Danish multidisciplinary pain center. *Pain*, 73, 393-400.
- BenDebba, M., Torgerson, W., S., Long, D., M. (1997). Personality traits, pain duration and severity, functional impairment, and psychological distress in patients with persistent low back pain. *Pain*, 72, 115-125.
- Bengtsson, A., Backman, E., Lindblom, B., & Skogh, T. (1994). Long term follow-up of FMS patients: clinical symptoms, muscular function, laboratory tests – an eight year comparison study. *Journal of Musculoskeletal Pain*, 2, 67-80.
- Bennett, R. M. (1989). Fibrositis (pp. 541-553). In Kelly, W. N., Harris, E. D., Ruddy, S., & Sledge, C. B. (Eds.). *Textbook of Rheumatology* (3<sup>rd</sup> Ed.). Philadelphia: WB Saunders.
- Bennett, R. M. (1989b). Beyond FMS: ideas on aetiology and treatment. *The Journal of Rheumatology* 16 (Supplement 19), 185-191.
- Bennett, R. M., Burckhardt, C. S., Clark, S. R., Reilly, C. A., Wiens, A. N., & Campbell, S. M. (1996). Group treatment of FMS: a six month outpatient programme. *The Journal of Rheumatology*, 23, 521-528.
- Bennett, R. M. & Jacobsen, S. (1994). Muscle function and origin of pain in FMS. *Bailliere's Clinical Rheumatology*, 8(4), 721-746.
- Benoliel, J. Q. (1996). Grounded theory and nursing knowledge. *Qualitative Health Research*, 6(3), 406-428.
- Block, S. R. (1993). FMS and the rheumatism: Common sense and sensibility. *Rheumatic Disease Clinics of North America*, 19(1), 61-78.
- Bloomfield, J., Fricker, P. A., & Fitch, K. D. (1992). *Textbook of Science and Medicine in Sport*. London: Blackwell Scientific Publications.
- Boissevain, M. D. & McCain, G. A. (1991). Toward an integrated understanding of FMS Syndrome: I. Medical and pathophysiological aspects. *Pain*, 45, 227-238.
- Bolwijn, P. H., van Santen-Hoeufft, M. H. S., Baars, H. M. J., & van der Linden, S. (1994). Social network characteristics in FMS or rheumatoid arthritis. *Arthritis Care and Research*, 7(1), 46-49.
- Bond, M. (1987). Psychology of pain. In S. Andersson, M. Bond, M. Mehta, & M. Swerdlow. *Chronic Non-Cancer Pain: Assessment and Practical Management*. MTP Press Limited: Lancaster, England.

- Borkovec, T. (1982). Insomnia. *Journal of Consulting and Clinical Psychology*, 50, 880-895.
- Brattberg, G., Parker, M. G., & Thorslund, M. (1997). A longitudinal study of pain: Reported pain from middle age to old age. *The Clinical Journal of Pain*, 13, 144-149.
- Brattberg, G., Thorslund, M., & Wikman, A. (1989). The prevalence of pain in a general population: the results of a postal survey in a county of Sweden. *Pain*, 37, 215-222.
- Brook, R. H. (1994). Appropriateness: the next frontier. *British Medical Journal*, 308, 218.
- Bryman, A. (1988). *Quantity and Quality in Social Research*. London: Unwin Hyman Ltd.
- Buchanan, D. R. (1992). An uneasy alliance: Combining qualitative and quantitative research methods. *Health Education Quarterly*, 19(1), 117-135.
- Burckhardt, C. S., Clark, S. R., & Bennett, R. M. (1993). FMS and quality of life: a comparative analysis. *The Journal of Rheumatology*, 20, 457-459.
- Burger, J. M. (1993). *Personality* (3<sup>rd</sup> Ed.). Pacific Grove, California: Brooks/Cole Publishing Company.
- Chaplin, J. P. (1985). *Dictionary of Psychology* (2<sup>nd</sup> Ed.). New York: Laurel.
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine*, 30(11), 1161-1172.
- Cathey, M. A., Wolfe, F., Kleinheksel, S. M., & Hawley, D. J. (1986). Socioeconomic impact of fibrositis: a study of 81 patients with primary fibrositis. *American Journal of Medicine* 81 (Supplement 3A), 78-84. **DON'T HAVE!!**
- Cheek, J. (1996). Taking a view: Qualitative research as representation. *Qualitative Health Research*, 6(4), 492-505.
- Chenitz, W. C. & Swanson, J. (1986). Qualitative research using grounded theory. In W. C. Chenitz & J. M. Swanson (Eds.). *From Practice to Grounded Theory: Qualitative Research in Nursing* (pp. 3-15). Menlo Park, CA: Addison-Wesley.
- Clark, S., Campbell, S. M., Forehand, M. E., Tindall, E. A., & Bennett, R. M. (1985). Clinical characteristics of fibrositis. II. A "blinded", controlled study using standard psychological tests. *Arthritis & Rheumatism*, 28, 132-137.
- Copp, L. A. (1986). Pain coping. In L. A. Copp. *Perspectives on Pain* (pp. 3-16). New York: Churchill Livingstone.
- Corbin, J. (1986). Qualitative data analysis for grounded theory. *From Practice to Grounded Theory: Qualitative Research in Nursing* (pp. 91-101). Menlo Park, CA: Addison-Wesley.

Corbin, J. & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.

Council, J. R., Ahern, D. K., Follick, M. J., & Kline, C. L. (1988). Expectancies and functional impairment in chronic low back pain. *Pain*, 33, 323-331.

Croft, P., Schollum, J., & Silman, A. (1994). Population study of tender point counts and pain as evidence on FMS. *British Medical Journal*, 309, 696-699.

Crombez, G., Vervaeke, L., Baeyens, F., Lysens, R., & Eelen, P. (1996). Do pain expectancies cause pain in chronic low back patients? A clinical investigation. *Behaviour Research & Therapy*, 34(11/12), 919-925.

Crook, J., Rideout, E., & Browne, G. (1984). The prevalence of pain complaints in a general population. *Pain*, 18, 299-314.

Dworkin, R. H., Hartstein, G., Rosner, H. L., Walther, R. R., Sweeney, E. W., & Brand, L. (1992). A high-risk method for studying psychosocial antecedents of chronic pain: The prospective investigation of herpes zoster. *Journal of Abnormal Psychology*, 101, 200-205.

Eccleston, C., Crombez, G., Aldrich, S., & Stannard, C. (1997). Attention and somatic awareness in chronic pain. *Pain*, 72, 209-215.

Ediger, B. (1991). *Coping with FMS*. U.S.A.: LRH Publications.

Edwards, L. C., Pearce, S. A., & Beard, R. W. (1995). Remediation of pain-related memory bias as a result of recovery from chronic pain. *Journal of Psychosomatic Research*, 39, 175-181.

Fagerhaugh, S. Y. (1986). Analyzing data for basic social processes. *From Practice to Grounded Theory: Qualitative Research in Nursing* (pp. 133-154). Menlo Park, CA: Addison-Wesley.

Feine, J. S. & Lund, J. P. (1997). An assessment of the efficacy of physical therapy and physical modalities for the control of chronic musculoskeletal pain. *Pain*, 71, 5-23.

Felson, D. T. & Goldenberg, D. L. (1986). The natural history of FMS. *Arthritis & Rheumatism*, 29, 1522-1526.

Flor, H. & Birbaumer, N. (1985). Assessment of stress-related psychophysiological reactions in chronic back pain patients. *Journal of Consultation & Clinical Psychology*, 53, 354-364.

#### **FMAGW (1995). General Information About FMS**

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology*, 46, 839-852.

- Gaston-Johansson, F., Gustafsson, M., Felldin, R., & Sanne, H. (1990). A comparative study of feelings, attitudes, and behaviours of patients with FMS and rheumatoid arthritis. *Social and Science Medicine*, 31(8), 941-947.
- Geisser, M. E., Roth, R. S., Bachman, J. E., & Eckert, T. A. (1996). The relationship between symptoms of post-traumatic stress disorder and pain, affective disturbance and disability among patients with accident and non-accident related pain. *Pain*, 66, 207-214.
- Gil, K. M., Keefe, F. J., Crisson, J. E., & Van Dalfsen, P. J. (1987). Social support and pain behaviour. *Pain*, 29, 209-217.
- Gildenberg, P. L. & DeVaul R. A. (1985). *The Chronic Pain Patient: Evaluation and Management*. Basel (Switzerland): Karger.
- Glaser, B. G. (1978). *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1992). *Emergence vs Forcing: Basics fo Grounded Theory Analysis*. Mill Valley, CA: Sociology.
- Glaser, B. G. & Strauss, A. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine.
- Goldenberg, D. L. (1986). Psychological studies in fibrositis. *American Journal of Medicine*, 81, 67-70.
- Greenfield, S., Fitzcharles, M. A., & Esdaile, J. M. (1992). Reactive FMS Syndrome. *Arthritis & Rheumatism*, 35(6), 678-681.
- Hagglund, K. J., Deuser, W. E., Buckelew, J. H., & Kay, D. R. (1994). Weather, beliefs about weather, and disease severity among patients with FMS. *Arthritis Care and Research*, 7(3), 130-135.
- Harkins, W. E., Price, D. D., & Braith, J. (1989). Effects of extraversion and neuroticism relation to pain, activity, and sex differences. *Pain*, 36, 209-218.
- Harvey, C. K., Cadena, R., & Dunlap, L. (1993). FMS: Part I. Review of the literature. *Journal of the American Podiatric Medical Association*, 83(7), 412-415.
- Hawley, D. J. & Wolfe, F. (1991). Pain, disability, and pain/disability relationships in seven rheumatic disorders: A study of 1, 522 patients. *The Journal of Rheumatology*, 18(10), 1552-1557.
- Haythornthwaite, J. A., Hegel, M. T., & Kerns, R. D. (1991). Development of a sleep diary for chronic pain patients. *Journal of Pain and Symptom Management*, 6(2), 65-72.
- Haythornthwaite, J. A., Menefee, L. A., Heinberg, L. J., & Clark, M. R. (1998). Pain coping strategies predict perceived control over pain. *Pain*, 77, 33-39.

- Henriksson, K. G. & Bengtsson, A. (1990). FMS – a clinical entity? *Canadian Journal of Physiological Pharmacology*, *69*, 672-677.
- Henriksson, C., Cundmark, I., Bengtsson, A., & Ek, A. (1992). Living with FMS. *The Clinical Journal of Pain*, *8*, 138-144.
- Henriksson, K. G. (1994). Chronic muscular pain: Aetiology and pathogenesis. *Balliere's Clinical Rheumatology*, *8*(4), 703-719.
- Henwood, K. & Pidgeon, N. (1994). Beyond the qualitative paradigm: A framework for introducing diversity within qualitative psychology. *Journal of Community & Applied Social Psychology*, *4*, 225-238.
- Holmes, J. A. & Stevenson, C. A. Z. (1990). Differential effects of avoidant and attentional coping strategies on adaptation to chronic and recent-onset pain. *Health Psychology*, *9*(5), 577-584.
- Horn, S. & Munafo, M. (1997). *Pain: Theory, research, and intervention*. Buckingham: Open University Press.
- Hudson, J. I., Judson, M. S., Pliner, L. F., Goldenberg, D. L., & Pope, H. G. J. (1985). FMS and major affective disorder: a controlled phenomenology and family history study. *American Journal of Psychiatry*, *142*, 441-446.
- Irurita, V. F. (1996). Hidden dimensions revealed: Progressive grounded theory study of quality care in the hospital. *Qualitative Health Research*, *6*(3), 331-349.
- Jacobsen, S., Danneskiold-Samsøe, B., Lund, B., eds (1993). Musculoskeletal pain, myofascial pain syndrome, and FMS syndrome. **Proceedings of the 2<sup>nd</sup> World Congress on Myofascial Pain and FMS.** *Journal of Musculoskeletal Pain*, *1*(3/4), 1-324.
- Jaeger, M. E. & Rosnow, R. L. (1988). 'Contextualism and its implications for psychological inquiring'. *British Journal of Psychology*, *79*, 63-75.
- James, F. R., Large, R. G., Bushnell, J. A., & Wells, J. E. (1991). Epidemiology of pain in New Zealand. *Pain*, *44*, 279-283.
- Jamison, R. N. & Virts, K. L. (1990). The influence of family support on chronic pain. *Behaviour Research & Therapy*, *28*(4), 283-287.
- Jensen, M. P., Turner, J. A., & Romano, J. M. (1991). Self-efficacy and outcome expectancies: Relationship to chronic pain coping strategies and adjustment. *Pain*, *44*, 263-269.
- Jensen, M. P., Turner, J. A., Romano, J. M., & Lawler, B. K. (1994). Relationships of pain-specific beliefs to chronic pain adjustment. *Pain*, *57*, 301-309.
- Kahler-Hench, P., Miller, M. M., & Merrill, M. (1986). FMS management guidelines, and research findings. *Postgraduate Medicine*, *80*, 57-60.

- Kalyan-Raman, U. P., Kalyan-Raman, K., Yunus, M. B., & Masi, A. T. (1984). Muscle pathology in primary FMS syndrome: a light microscopic, histochemical and ultrastructural study. *The Journal of Rheumatology*, *11*(6), 808-813.
- Keddy, B., Sims, S. L., & Stern, P. N. (1996). Grounded theory as feminist research methodology. *Journal of Advanced Nursing*, *23*, 448-453.
- Kearney, M. H., Murphy, S., & Rosenbaum, M. (1994). Mothering on crack cocaine: A grounded theory analysis. *Social Science & Medicine*, *38*(2), 351-361.
- Keefe, F. J., Kashikar-Zuck, S., Robinson, E., Sallely, A., Beaupre, P., Caldwell, D., Baucom, D., & Haythornthwaite, J. (1997). Pain coping strategies that predict patient's and spouses' rating of patients' self-efficacy. *Pain*, *73*, 191-199.
- Keefe, F. J., Salley, A. N., & Lefebvre, J. C. (1992). Coping with pain: Conceptual concerns and future direction. *Pain*, *51*, 131-134.
- Kelley, P. & Clifford, P. (1997). Coping with chronic pain: Assessing narrative approaches. *Social Work*, *42*(3), 266-277.
- Kerns, R. D., Rosenberg, R., Jamison, R. N., Caudill, M. A., & Haythornthwaite, J. (1997). Readiness to adopt a self-management approach to chronic pain: The Pain Stages of Change Questionnaire (PSOCQ). *Pain*, *72*, 227-234.
- Koutantji, M., Pearce, S. A., & Oakley, D. A. (1998). The relationship between gender and family history of pain with current pain experience and awareness of pain in others. *Pain*, *77*, 77-31.
- Krag, N. J., Norregard, J., Larsen, J. K., & Danneskiold-Samsoe, B. (1994). A blinded, controlled evaluation of anxiety and depressive symptoms in patients with FMS, as measured by standardised psychometric interview scales. *Acta Psychiatrica Scandinavica*, *89*, 370-375.
- Krishman, K. R., France, R. D., Pelton, S., McCann, V. D., Davidson, J., & Urban, B. J. (1985). Chronic pain and depression. I. Classification of depression in chronic low back pain. *Pain*, *22*, 279-289.
- Kurtze, N., Gundersen, K. T., & Svebak, S. (1998). The role of anxiety and depression in fatigue and patterns of pain among subgroups of FMS patients. *British Journal of Medical Psychology*, *71*, 185-194.
- Lautenbacher, S., Rollman, G. B., & McCain, G. A. (1994). Multi-method assessment of experimental and clinical pain in patients with FMS. *Pain*, *59*, 45-53.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Leininger, M. (1992). Current issues, problems, and trends to advance qualitative paradigmatic research methods for the future. *Qualitative Health Research*, *2*(4), 392-415.

- Linton, S. J. (1998). The socioeconomic impact of chronic back pain: Is anyone benefiting? *Pain*, *75*, 163-168.
- Lofland, J. (1971). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*. Belmont, California: Wadsworth Publishing Co.
- Lofland, J. & Lofland, L. H. (1995). *Analyzing Social Settings: A guide to qualitative Observation and Analysis* (3<sup>rd</sup> Ed.). Belmont CA: Wadsworth.
- Lund-Olesen, L. H. & Lund-Olesen, K. (1994). The etiology and possible treatment of chronic fatigue syndrome/FMS. *Medical Hypotheses*, *43*, 55-58.
- McCracken, L. M. (1998). Learning to live with the pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain*, *74*, 21-27.
- McCracken, L. M., Klock, P. A., Mingay, D. J., Asbury, J. K., & Sinclair, D., M. (1997). Assessment of satisfaction with treatment for chronic pain. *Journal of Pain and Symptom Management*, *14*(5), 292-299.
- McGrath, P. A. (1993). Psychological aspects of pain perception. In N. L. Schechter, C. B. Berde, & M. Yaster (Eds.). *Pain in Infants, Children, and Adolescents: An Overview* (pp. 39-63). Baltimore, Maryland: Williams & Wilkins.
- Magni, G., Moreschi, C., Rigatti-Luchini, S., & Mersky, H. (1994). Prospective study on the relationship between depressive symptoms and the chronic musculoskeletal pain. *Pain*, *56*, 289-297.
- Main, C. J. & Waddell, G. (1991). A comparison of cognitive measures in low back pain: Statistical structure and acinical validity at initial assessment. *Pain*, *46*, 287-298.
- Marshall, C. & Rossman, G. B. (1995). *Designing Qualitative Research* (2<sup>nd</sup> ed.). Thousand Oaks, California: Sage Publications, Inc.
- Martin, P. Y. & Turner, B. A. (1987). Grounded theory and organisational research. *Journal of Applied Behavioural Science*, *22*(2), 141-157.
- Masi, A. T. (1994). An intuitive person-centred perspective on FMS syndrome and its management. *Bailliere's Clinical Rheumatology*, *8*(4), 957-993.
- Masi, A. T. & Yunus, M. B. (1986). Concepts of illness in populations as applied to fibromyalgia: Concepts of illness in populations as applied to dysfunctional syndromes. *Journal of Musculoskeletal Pain*, *1*, 113-136.
- Mason, L. W., Goolkasian, P., & McCain, G. A. (1998). Evaluation of a multimodal treatment program for FMS. *Journal of Behavioral Medicine*, *21*(2), 163-178.
- Mersky, H. (1989). Physical and psychological considerations in the classification of FMS. *The Journal of Rheumatology* *16* (Supplement 19), 72-79.

- Merskey, H. & Bogduk, N. (1994). *Classification of Chronic Pain: Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms* (2<sup>nd</sup> Ed.). IASP Press: Seattle.
- Miller, L. (1993). Psychotherapeutic approaches to chronic pain. *Psychotherapy*, 30, 115-124.
- Mishler, E. G. (1986). *Research Interviewing: Context and Narrative*. Cambridge, MA: Harvard University Press.
- Moissevain, M. D. & McCain, G. A. (1991). Toward an integrated understanding of FMS Syndrome: II. Psychological and phenomenological aspects. *Pain*, 45, 239-248.
- Moldofsky, H., Scarisbrick, P., England, R., & Smythe, H. (1975). Musculoskeletal symptoms and non-REM sleep disturbance in patients with 'fibrositis syndrome' and healthy subjects. *Psychosomatic Medicine*, 37, 341-351.
- Neimeyer, R. A. (1993). An appraisal of constructivist psychotherapies. *Journal of Consulting and Clinical Psychology*, 61, 221-234.
- Neumann, L. & Buskila, D. (1997). Quality of life and physical functioning of relatives of FMS patients. *Seminars in Arthritis and Rheumatism*, 26(6), 834-839.
- Neumann, W., Kugler, J., Pfand-Neumann, P., Schmitz, N., Seelbach, H., Kruskemper, G. M. (1997). Effects of pain-incompatible imagery on tolerance of pain, heart rate, and skin resistance. *Perceptual and Motor Skills*, 84, 939-943.
- Newman, S., Fitzpatrick, R., Lamb, R., & Shipley, M. (1990). An analysis of coping patterns in Rheumatoid Arthritis. In L. R. Schmidt, P. Schwenkmezger, J. Weinman, & S. Maes (Eds.). *Theoretical and Applied Aspects of Health Psychology*. Amsterdam: Harwood Academic.
- Olshansky, E. F. (1996). Theoretical issues in building a grounded theory: Application of an example of a program of research on infertility. *Qualitative Health Research*, 6(3), 394-405.
- Pellegrino, M. J. (1990). Atypical chest pain as an initial presentation of primary FMS. *Archive of Physiology and Medical Rehabilitation*, 71, 526-528.
- Perry, F., Heller, P., & Levine, J. (1988). Differing correlations between pain measures in syndromes without explicable organic pathology. *Pain*, 34, 185-189.
- Peters, M. L. & Schmidt, A. J. M. (1991). Psychophysiological responses to repeated acute pain stimulation in chronic low back pain patients. *Journal of Psychosomatic Research*, 35(1), 59-74.
- Philips, H. C. (1987). Avoidance behaviour and its role in sustaining chronic pain. *Behaviour Research and Therapy*, 25, 273-279.
- Raymond, B. & Bergland, M. M. (1994). Psychosocial aspects of FMS syndrome. *Journal of Applied Rehabilitation Counseling*, 25 (3), 42-46.

- Reilly, P. A. (1993). FMS in workplace: a management problem. *Annals of the Rheumatic Diseases*, 52, 249-251.
- Robbins, J. M., Kirmayer, L. J., & Kapusta, M. A. (1990). Illness worry and disability in FMS Syndrome. *International journal of Psychiatry in Medicine*, 20(1), 49-63.
- Robrecht, L. C. (1995). Grounded theory: Evolving methods. *Qualitative Health Research*, 5(2), 169-177.
- Romano, J. M. & Turner, J. A. (1985). Chronic pain & depression: Does the evidence support a relationship? *Psychology Bulletin*, 97(1), 18-34.
- Roy, R. (1989). *Chronic Pain and the Family*. New York: Human Sciences press.
- Rudy, T. E., Kerns, R. D., & Turk, D. C. (1988). Chronic pain and depression: toward a cognitive-behavioural mediation model. *Pain*, 35, 129-140.
- Sarnoch, H., Adler, F., & Berndt Scholz, O. (1997). Relevance of muscular sensitivity, muscular activity, and cognitive variables for pain reduction associated with EMG biofeedback in FMS. *Perceptual and Motor Skills*, 84, 1403-1050.
- Schneider, M. J. (1995). Tender points/FMS vs. Trigger Points/Myofascial Pain Syndrome: A need for clarity in terminology and differential diagnosis. *Journal of Manipulative and Physiological Therapeutics*, 18(6), 398-406.
- Simms, R. W., Goldenberg, D. L., Felson, D. T., & Mason, J. H. (1988). Tenderness in 75 anatomic sites: distinguishing FMS patients from controls. *Arthritis & Rheumatism*, 31, 182-187.
- Sist, T. C., Florio, G. A., Miner, M. F., Lema, M. J., & Zeovon, M. A., (1998). The relationship between depression and pain language in cancer and chronic non-cancer pain patients. *Journal of Pain and Symptom Management*, 15(6), 350-358.
- Skevington, S. M. (1998). Investigating the relationship between pain and discomfort and quality of life, using the WHOQOL. *Pain*, 76, 395-406.
- Smythe, H. A., Bennett, R. M., & Wolfe, F. (1993). Recognizing FMS. *patient Care*, 27, 53-72.
- Stanley, L. & Wise, S. (1983). *Breaking Out: Feminist Consciousness and Feminist Research*. Lndon: Routledge & Kegan Paul.
- Starlanyl, D. J. & Copeland, M. E. (1996). *FMS and Chronic Myofascial Pain Syndrome: A Survival Manyal*. Oakland, California: New Harbinger Publications.
- Stern, D. N. S. (1980). Grounded theory methodology: Its uses and processes. In B. G. Glaser (1995). *Grounded Theory: 1984 – 1994*. Mill Valley, CA: Sociology Press.

Sternbach, R. A. (1982). The psychologist's role in the diagnosis and treatment of pain patients. In J. Barber & C. Adrian. *Psychological Approaches to the Management of Pain* (pp. 3-20). New York: Brunner/Mazel, Inc.

Stone, A., Broderick, J., Porter, L., Krupp, L., Gnys, M., Paty, J., & Shiffman, S. (1994). Fatigue and mood in chronic fatigue syndrome patients: Results of a momentary assessment protocol examining fatigue and mood levels and diurnal patterns. *Annals of Behavioral Medicine*, 16, 228-234.

Strauss, A. L. (1987). *Qualitative Analysis for Social Scientists*. San Francisco: Cambridge University Press.

Strauss, A. & Corbin, J. (1990). *Basic of Qualitative Research: Grounded theory, procedures and techniques*. Beverly Hills, CA: Sage.

Strauss, A. & Corbin, J. (1994). Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Strong, J., Ashton, R., & Chant, D. (1992). The measurement of attitudes towards and beliefs about pain. *Pain*, 42, 227-236.

Suls, J. & Fletcher, E. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta-analysis. *Health Psychology*, 4, 249-288.

Swanson, J. M. (1986). The formal qualitative interview for grounded theory. In W. C. Chenitz & J. M. Swanson (Eds.). *From Practice to Grounded Theory: Qualitative Research in Nursing* (pp. 67-78). Menlo Park, CA: Addison-Wesley.

Thompson, S. C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. *Psychological Bulletin*, 90, 89-101.

Totterdell, P., Reynolds, S., Parkinson, B., & Briner, R. (1994). Associations of sleep with everyday mood, minor symptoms, and social interaction experience. *Sleep*, 17, 466-475.

Turk, D. C., Meichenbaum, D., & Genest, M. (1983). *Pain and Behavioral Medicine: A Cognitive-Behavioral Perspective*. New York: Guilford Press.

Turk, D. C., Okifuji, A., Starz, T. W., & Sinclair, J. D. (1996). Effects of type of symptom onset on psychological distress and disability in FMS Syndrome patients. *Pain*, 68, 423-430.

Turk, D. C., Rudy, T. E., & Sorkin, B. A. (1993). Neglected topics in chronic pain treatment outcome studies: determination of success. *Pain*, 53, 3-16.

Turner, J. A., Clancy, S., & Vitaliano, P. P. (1987). Relationships of stress, appraisal, and coping to chronic low back pain. *Behavior Research & Therapy*, 25(4), 281-288.

Ty, T. C., Melzack, R., & Wall, P. D. (1989). Acute trauma. In P. D. Wall & R. Melzack (Eds.), *Textbook of Pain* (pp. 209-214). Edinburgh: Churchill Livingstone.

Urrows, S., Affleck, G., Tennen, H., & Higgins, P. (1994). Unique clinical and psychological correlates of FMS tender points and joint tenderness in rheumatoid arthritis. *Arthritis & Rheumatism*, 37(10), 1513-1520.

Uveges, J. M., Parker, J. C., Smarr, K., L., McGowan, J. F., Lyon, M. G., Irvin, W. S., Meyer, A. A., Buckelew, S. P., Morgan, R. K., Delmonico, R. L., Hewett, J. E., & Kay, D. R. (1990). Psychological symptoms in primary FMS syndrome: relationship to pain, life stress, and sleep disturbance. *Arthritis & Rheumatism*, 33(8), 1279-1283.

Vendrig, A. A. Lousberg, R. (1997). Within-person relationships among pain intensity, mood and physical activity in chronic pain: A naturalistic approach. *Pain*, 73, 71-76.

Violon, A. (1990). The process involved in becoming a chronic pain patient. In E. Tunks, A. Bellissimo, & R. Roy (Eds.), *Chronic Pain: Psychosocial Factors in Rehabilitation* (pp. 21-36). Malabar, FL: Robert E. Krieger.

Vitiliano, P. P., DeWolfe, D. J., Maiuro, R. D., Russo, J., & Katon, W. (1990). Apprased changeability of a stressor as a modifier of the relationship between coping and depression: A test of the hypothesis of fit. *Journal of Personality and Social Psychology*, 59, 582-592.

Vlaeyen, J. W. S., Kole-Snijders, A. M. J., Boeren, R. G. B., & van Eek, H. (1995). Fear of movement/(re)injury in chronic low back pain and its relation to behavioral performance. *Pain*, 62, 363-372.

Waddell, G., Pilowsky, I., & Bond, M. R. (1989). Clinical assessment and interpretation of abnormal illness behaviour in low back pain. *Pain*, 39, 41-53.

Waddell, G., Newton, M., Henderson, I., Somerville, D., & Main, C. J. (1993). A fear-Avoidance Beliefs Questionnaire (FABQ) and the role of fear-avoidance beliefs in chronic low back pain and disability. *Pain*, 52, 157-168.

Wade, J. B., Dougherty, L. M., Hart, R. P., Rafii, A., & Price, D. D. (1992). A canonical correlation analysis of the influence of neuroticism and extraversion on chronic pain, suffering, and pain behaviour. *Pain*, 51, 67-73.

Wall, P. D. (1989). Pain and the placebo response. In P. D. Wall and R. Melzack (Eds.), *Textbook of Pain* (2<sup>nd</sup> Ed.). Edinburgh: Churchill Livingstone.

Wallace, D. J. (1997). The FMS Syndrome. *The Finnish Medical Society, DUODECIM, Annual Medicine*, 29, 9-21.

Waylonis, G. W., Ronan, P. G., Gordon, C. (1994). A profile of FMS in occupational environments. *American Journal of Physical Medicine and Rehabilitation*, 112-115.

Weiten, W. (1992). *Psychology: Themes and Variations* (2<sup>nd</sup> Ed.). Pacific Grove, California: Brooks/Cole Publishing Company.

White, C. L., LeFort, S. M., Amsel, R., & Jeans, M. (1997). Predictors of the development of chronic pain. *Research in Nursing & Health*, 20, 309-318.

Wilke, W. S. & Corbo, D. D. (1989). Fibromsitis/FMS: causes and treatment. *Comprehensive Therapy*, 15(1), 47-54.

Wilson, H. S. & Hutchinson, S. A. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research*, 1(2), 263-276.

Wilson, H. S. & Hutchinson, S. A. (1996). Methodologic mistakes in grounded theory. *Nursing Research*, 45(2), 12-124.

White, K. P., Harth, M., & Teasell, R. W. (1995). Work disability evaluation and the FMS syndrome. *Seminars in Arthritis and Rheumatism*, 24 (6), 371-381.

Wolf, F. (1990). FMS. *Rheumatoid Disease Clinics of North America*, 16, 681-698.

Wolf, F., Smythe, H. A., Smythe, H. A., Yunus, M. B., Bennett, R. M., Bombardier, C., Goldenberg, D. L., Tugwell, P., Campbell, S. M., Abeles, M., Clark, P., Fam, A. G., Farber, S. J., Fiechtner, J. J., Franklin, C. M., Gatter, R. A., Hamaty, D., Lessard, J., Lichtbroun, A. S., Masi, A. T., McCain, G. A., Reynolds, W. J., Romano, T. J., Russell, I. J., & Sheon, R. J. (1990). The American College of Rheumatology 1990 criteria for the classification of FMS. Report of the Multicenter Criteria Committee. *Arthritis Rheumatology*, 33, 160-172.

Wolfe, F., Ross, K., Anderson, J., Russell, I. J., & Hebert, L. (1995). The prevalence and characteristics of FMS in the general population. *Arthritis & Rheumatism*, 38, 19-28.

Wolfe, F. (1997). The relation between tender points and FMS symptom variables: evidence that FMS is not a discrete disorder in the clinic. *Annals of the Rheumatic Diseases*, 56, 268-271.

Wuest, J. (1995). Feminist grounded theory: An exploration of the congruency and tensions between two traditions in knowledge discovery. *Qualitative Health Research*, 5(1), 125-137.

Yunus, M. B. & Masi, A. T. (1985). Juvenile FMS syndrome: a clinical study of 35 patients and matched normal controls. *Arthritis & Rheumatism*, 28, 138-145.

Yunus, M. B. (1988). Diagnosis, etiology, and management of FMS syndrome: An update. *Comprehensive Therapy*, 14(4), 8-20.

Yunus, M. B., Ahles, T. A., Aldag, J. C., & Masi, A. T. (1991). Relationship of clinical features with psychological status in primary FMS. *Arthritis & Rheumatism*, 34(1), 15-21.

Yunus, M. B. (1994). Psychological aspects of FMS syndrome: a component of the dysfunctional spectrum syndrome. *Bailliere's Clinical Rheumatology*, 8(4), 811-837.

## **Appendix I**

### **CRITERIA FOR JUDGING QUALITATIVE RESEARCH**

The philosophical paradigm emphasises the contrast between the knower and the known. The objective is to minimise the potential consequences of research bias that deviates from empirical evidence. A set of guiding criterion has being developed to evaluate the austerity and exactitude of qualitative research without thwarting the creativity and insight of the qualitative researcher (e.g. Henwood & Pidgeon, 1992; Marshall & Rossman, 1995; Stiles, 1990).

No single methodological criterion can serve to testify and ensure the complete accuracy and validity of an emergent theory, either independently or collectively with other criteria (Henwood & Pidgeon, 1992; Stiles, 1990). However, by identifying the methodology conducted in a specific field of study, a combination of criteria practice to illustrate the trustworthiness of qualitative research results. An amalgamation of Stiles (1990) qualitative research criteria and by Henwood & Pideon (1992) criterion of quality for grounded theory methodology were chosen for the present research. Each criterion was chosen for its relevance and trustworthiness concerning the research results.

#### **Catalytic Validity (Stiles, 1990)**

An emergent theory will be effective for the participants if it is authentic and fits the data. This criterion is concerned with the quality of data interpretation and its empowering effect to change, pinpoint, and invigorate participants. A catalytically valid interpretation can stimulate participants to change.

#### **Coherence (Stiles, 1990). Keeping close to the data: The importance of fit (Henwood & Pidgeon, 1992)**

These two criteria characterise the quality of researcher's interpretation and the consistency or fit between the data and emergent theory respectively. Both of these are concerned with the goodness of fit. A good interpretation should have internal consistency, encompass relationships between constructs, and have effective interpretation of new constructs as well as rivals. The primary objective is to summarise with comprehensive definitions why data or investigated phenomena have been

characterised with particular descriptions. The researcher also must acknowledge preconceptions, expectations, and biases.

### **Confirmability (Lincoln & Cuba, 1985; Marshall & Rossman, 1995)**

Seizing the traditional concept of objectivity, this criterion emphasis the need to testify whether preliminary results can validate the research findings by asking: "Do the present data help confirm the general findings and lead to the implications?" (Marshall & Rossman, 1995, p. 145)

### **Consensus among researchers (Stiles, 1990)**

This pragmatic criterion does not ensure validity singularly because of its inherent weaknesses in relation to conformity pressures. In addition to the researcher's interpretation, that of others which conform can only strengthen the trustworthiness and validness of the research.

### **Theory integrated at diverse levels of abstraction (Henwood & Pidgeon, 1992)**

The key question to ask here is "*Does the theory work?*" For a theory to work (Glaser, 1978), the analysis of data and level of conceptual integration needs to be done at various levels of theoretical abstractions of categories and properties to ensure that the emerging theory is relevant to the investigated phenomenon to a point at which generality is achieved. The more abstract the concept(s), particularly the core category, the wider the applicability of the theory.

### **Theoretical sampling and negative case analysis (Henwood & Pidgeon, 1992)**

This criterion is characterised by an intention to identify negative scenarios that do not fit the emergent conceptual framework. This criterion advocates the necessity of constant comparative analysis in order to uncover and challenge theoretically incoherent cases of data with the purpose of modifying and elaborating on emergent theory.

### **Testimonial validity (Stiles, 1990). Sensitivity to negotiated realities (Henwood & Pidgeon, 1992)**

Both testimonial validity and sensitivity to negotiated realities share the objective of verifying with participants the researcher's interpretation. Through a constructive process of joint negotiation of reality, the researcher and individual participant overcomes the

potential difficulties of respondent validation such as participants' unawareness of reasons for their actions. The validity check in the present research was negotiating realities with the participants during the interviews by immediately interpreting participants' phrases and asking for feedback until the researcher was clear. Such techniques can prevent integrating multiple story lines and allows the target group to be true participants in the research (Keddy, Sims, & Stern, 1996).

**Triangulation (Stiles, 1990; Marshall & Rossman, 1995)**

Triangulation is conducted by a combination of multiple qualitative and quantitative methods and previous research and theories with an aim to check source coherence against present research findings (Leininger, 1992; Marshall & Rossman, 1995). The transferability of a study can be reinforced by triangulating multiple sources of data. Triangulation of data within interviews was addressed in this study by asking for participants' global experience of FMS under five broad themes.

## Appendix II

### INTERVIEW QUESTIONS

\* The investigation will generally adhere to the following basic interview format. Modifications in interview format may be necessary.

#### Causation

- Q: Could you start off by telling me how and when did you first notice something was wrong with you?  
Anything in particular?
- Q: When/At what point did you first decide to seek (medical/professional) help?  
Why then?
- Q: How long have you had FMS?
- Q: What do you believe to have caused you FMS, in your own words? Why?
- Q: Do you think that the condition is caused or precipitated by any one factor/thing alone, or do you think it is caused by a combination of factors?
- Q: Can you think of any other factors/activities or otherwise that underlie that development of your FMS?
- Q: What do you consider to be the most important cause/determinant of your FMS?
- Q: Could you put these reasons in hierarchical order of the most important to the least important cause for you personally and in your opinion/own words?

#### Symptoms

- Q: When did you first notice the symptoms(s)?
- Q: What was/were it/they?
- Q: What are your symptoms?
- Q: Which is the most severe?
- Q: Which is the most commonly experienced?

**Example:** pain

When?

How? How did it happen?

- e.g. Where did depression/anxiety originate from?

Can you describe the pain?

Was the pain in more than one place?

Is there different types of pain?

Where/which part of your body?

For how long has it been with you?

How does pain affect you?

- cognitive, behavioural, motivational, neurological, etc.

Each time the pain occurs, how long did it last?

How did you feel when you were having pain?

What were you doing when you were having pain?

Does the pain typically occur during certain activities or is there no pattern of pain linked with your activities?

Did the pain go away by itself?

IF NO, what did you have to do to stop then pain?

Did pain go away then?

Is pain a recurrent event?/Does it happen from time to time?

How frequent?

Did pain get worse over time?

For you personally, what is the most salient/noticeable feeling/memory of the pain?

### **Personal Feelings**

Q: How did you first hear about FMS?

Q: What comes to your mind when you think of FMS?

Q: How do you feel about having FMS?

Q: (As you look back on your illness), which event(s) stood out in your mind?

Q: What does a good day mean to you?

What kinds of things do you do on a good day?

Could you described what a bad day is like?

How does FMS affect you on a daily basis?

What limitations, if any does FMS impose on you?

How do these activities compare with those on a bad day?

**Q:** Why do you think you end up with this problem – FMS?

**Q:** Why do you think you are the person with this problem? Why you, instead of others?

**Prompt** – they way you/people do things, etc.

**Q:** What do you think other people think happened to you?

**Prompt** – your partner, your family, your friends, your colleagues, etc.

**Q:** In medical terms, what signs/symptoms do you believe your specialist used to diagnose you with FMS?

**Q:** Do you feel differently about your FMS at different time of the day/week/month/year?

Why?

### Coping

**Q:** What's been the most difficult thing for you regarding FMS?

**Q:** How much do you think about your own physical health now? Any changes?

**Q:** Do you see yourself as being ill?

**Q:** What do you think this problem is gonna happen to you in the future?

**Q:** Do you practice any activities to eliminate FMS? What? Why?

**Q:** For you personally, what do you feel is the best way to deal with your FMS?

### Effects/Consequences

**Q:** How has FMS affected you?

**Prompt** – physically, emotionally/psychologically, cognitively, QOL, your everyday life, etc.

**Probe** – What are the changes?

Did you have to seek any help for emotional (etc.) problems? How?

**Q:** What do you think it affects on your symptoms?

**Q:** Can you describe for me what a typical day is like now?

How does it differ from your usual routine before this health problem?

**Q:** Do you feel differently about yourself since this problem began?  
**IF YES,** in what ways?

**Optional:**

**Q:** Could you talk about what independence means to you now?

**Q:** How has FMS affected your independence?  
 What in particular? For example .

*Be encouraging! By probing –*

- And then what happened? / What happens then?
- That was very interesting.
  - Could you tell me more about that?
  - Could we go back to what you were saying earlier about ... as I'd like you to tell me more about that ...
- Silence, pause for a few seconds
  - When ask open questions and still get brief, shallow answers.

## **Appendix III**

### **FACE SHEET**

Code Number:

Date of the Interview:

Interview Site:

Name:

Age:

Gender:

Marital Status:

Race/Ethnic Identity:

Education:

Current Occupation (if NONE, previous job):

Income:

Religion:

Others:

## Appendix IV

### NEWSPAPER ADVERTISEMENT

### Subjects required

Occupational Overuse Syndrome (OOS) is a broad umbrella term used by the medical fertility to describe a number of stress and strain increasingly suffered by contemporary work forces. Fibromyalgia (FMS) has been identified as one member of this family of conditions but with unknown causes. A study is proposed as a part of Massey University Masters thesis to identify the “aetiology/causes of fibromyalgia” from the patients’ perspective. If you have been diagnosed as suffering from this condition and are interested in participating in a interview-based study, please contact Maggie Cheng (researcher) for further information. Tel/Fax: [REDACTED] [REDACTED] [REDACTED] or email:

## Appendix V

### INFORMATION SHEET

**TITLE: Patients' Perspectives on Fibromyalgia Syndrome (FMS)**

#### INFORMATION SHEET

**Researcher:**

Maggie Cheng  
Department of Psychology  
Massey University  
Private Bag,  
Palmerston North



I am a student at Massey University enrolled in the M.A. programme in Psychology. My supervisor is Malcolm Johnson, senior lecturer of Department of Psychology. I have a particular interest in musculoskeletal rheumatology issues. This research project has the following goals:

- (i) To find out what patients think were the causes of their problems and why they think these causes had an effect.
- (ii) To see how fibromyalgia affects the sufferers' lives personally and occupationally.
- (iii) To investigate whether and how the patients' personal beliefs in any means affect the outcome of the illness.

I would sincerely appreciate your participation if you decide to assist with this survey/study by attending a one-to-one interview. The interview will take about an hour and will be audio-taped.

You have the right to refuse to take part in this study. You do not have to answer all questions, and you have the right to withdraw from this study at any time. This research will not in any means related to your clinic visit if existed.

If you are willing to participate in this study, please complete the attached Consent Form and mail it within the provided return envelope. If you have any questions, please do not hesitate to contact me at the above telephone number.

The collected data from this study will be retained securely and confidentially by my supervisor and me. No material, which could identify you personally, will be used in any written or verbal report.

A brief summary of the results of this study will be available from the Department of Psychology at Massey University with the actual date informed later.

Thank you for your time and assistance.

Maggie C. J Cheng

## Appendix VI

### CONSENT FORM

**TITLE: Patients' Perspectives on Fibromyalgia Syndrome (FMS)**

### CONSENT FORM

**Researcher:**

Maggie C. J. Cheng  
Department of Psychology  
Massey University  
Private Bag,  
Palmerston North  
Tel. (04) 476 9014

I have read the Information Sheet and have the details of the study explained to me. I understand the purpose and details of the study. I understand that I may contact the researcher for clarification on any issue.

I understand that I have the right to withdraw from participation in this study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher(s) on the understanding that my name will be not be used without my permission.

*(This information will be used only for this research and publication arising from this research project).*

I agree/do not agree to the interview being audio taped.

I also understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix VII

### SUMMARY OF FINDINGS FOR PARTICIPANTS

**TITLE: Patients' Perspectives on Fibromyalgia Syndrome (FMS)**

#### SUMMARY OF FINDINGS

**Researcher:**

Maggie C. J. Cheng  
Department of Psychology  
Massey University  
Private Bag,  
Palmerston North



Dear Participants,

Firstly, I would like to reiterate my thanks for your assistance in the formation of this research project. As a diagnosed sufferer of FMS, I hope this letter can help you, your family, and your friends to cope better through greater understanding of the FMS condition.

By using in-depth interviews, I was able to identify patterns of common meaning across participants' FMS experience. The novelty of the present research with its use of the patients' perspectives of their FMS condition revealed a rich and complex interrelated and interdependent series of occurrences that were grouped into seven aspects embodying the FMS condition. Specifically, these aspects included aetiology (cause), susceptible populations, FMS symptoms, intervening conditions (things that aggravated or improved symptoms), evolution & choice of coping strategies, treatment regime, and consequences.

Participants in this research described both reactive (with specific causal event) and idiopathic (without specific causal event) aetiologies consistent with the literature. However, unlike the literature, participants described combination of reactive and idiopathic aetiologies. In addition, greater support for multifactorial (more than one casual event) and hereditary causes emerged from participants' reports. Finally, although not directly linked to the cause of FMS, non-restorative/disturbed (abnormal) sleep patterns, trauma, and personality were described in association with the cause of FMS.

Although it may be an artefact of research recruitment, 82.5% of participants were female. This disproportionate representation of females with FMS concurred with literature, but would require further research before anything conclusive could be stated.

Participants described a range of physical, psychological, and cognitive symptoms because of their FMS condition. Typically, symptoms were interrelated in a cyclical manner that served to worsen or relieve symptom severity. The most salient physical FMS symptoms were chronic musculoskeletal pain and fatigue with pain penetrating every aspect of participants' FMS experience. Pain tended to be localised to articular surfaces (joints) and/or generalised across the musculoskeletal system. Being associated with the cause of FMS, sleep disturbance was also a common symptom amongst the participants in this study. Cognitive (thinking) symptoms included reduced concentration and impaired memory. Specific psychological problems consisted of distress, depression, anxiety, and mood swings. It appeared that many of these psychological symptoms were the result of public and professional misconception as to the legitimacy of FMS condition. These misconceptions lead participants to feeling frustration, doubt, and anxiety regarding their own beliefs of the existence of the FMS condition.

A number of factors appeared to mediate the severity of FMS conditions:

Financial Intervening Conditions	ACC	
	Work & Income New Zealand	
	Medical Costs	
Person-oriented Intervening Conditions	Associated manipulations	
	External influences	Arousal level
		Activity level
		Climatic conditions

	Personality & history	Type A personality Personality traits
Medical Intervening conditions	Misdiagnosis	
	Ineffective treatment	
	Insufficient knowledge	
	Complications	
	Medical practitioners' attitudes (personal beliefs about and feelings towards FMS)	
Information & Awareness Intervening Conditions	Active information & awareness (self-search and obtain material about FMS)	
	Limited information & awareness	Lack of access & knowledge about FMS
		Being provided with inaccurate counsel
Social Support Intervening Conditions	Occupational intervening conditions	Work location
		Workload
		Types of work
	Support intervening conditions (social and bureaucratic misconception such as invisibility and lack of recognition of FMS)	

These were referred to as intervening conditions and included financial, person-oriented, medical, information & awareness, and social support aspects. For instance, financial intervening conditions such as the insufficient compensation from ACC or Work & Income New Zealand appeared to aggravate FMS symptoms. Likewise, medical intervening conditions such as a lack of or delayed diagnosis, lack of educational material, and inappropriate treatment led to a decline in participants' physical and psychological states.

Coping strategies employed by FMS participants were grouped into four categories including cognitive, behavioural, cognitive-behavioural, and social support coping strategies:

COGNITIVE COPING STRATEGIES	Cognitive Resolution	
	Non-defeatist Attitude	
	Positive Deferral	
	Positive Self-talk	
	Relaxation	
	Imagery	
BEHAVIOURAL COPING STRATEGIES	Consulting Medical Practitioners	
	Behavioural Adjustment	Ergonomic relief
		Frequent movement
		Continuation with activities
		Exercise
		Continuation with activities
		Lifestyle limits
		Limitation of physical contact
		Being in control and/or monitoring
	Physical Interventions	Self-prescribed medication
		Self-prescribed physical interventions
		Active information seeking
		Self-management
COGNITIVE-BEHAVIOURAL COPING STRATEGIES	Distraction Strategies	
	Attentional Strategies	
	Intentional denial/Avoidance Strategies	
	Journal Keeping for Relaxation	
FAMILY & SOCIAL SUPPORT COPING STRATEGIES	Seeking Help	
	Spouse Support	
	Support Network	

For instance, participants used positive deferral as a cognitive coping strategy to help them ignore pain and symptoms. Generally, coping strategies increased in complexity and range as participants became more experienced and adaptable at using various coping strategies. This evolution in coping strategies and the associated successful use of coping strategies were linked to participants' self-efficacy (beliefs that they can cope).

By using behavioural coping strategies, participants described various physical adjustments to cope with FMS symptoms (listed above). Participants tended to adjust their behaviour to accommodate FMS pain while still trying to maintain a near as normal life possible.

Treatment regimes were based on participants' trial-and-error experiences to come up with the best combination of pharmacological (prescriptive), psychological, and physical therapies for relieving FMS symptoms. The trial-and-error approach to treatment emerged from unknown cases of FMS and how best to treat it. While coping strategies focused more on self-help, treatment regimes centred more on external sources of assistance, particularly from the medical-care practitioners.

The consequences of FMS were reported by participants in terms of impacts of their FMS condition upon the various aspects of their lives. Generally, participants experienced negative consequences on their physical and psychological health, relationships with their spouse, family, and friends, employment, financial status, as well as a decline in their quality of life. FMS consequences varied between participants although all reported daily fluctuation in the levels of overall FMS impact.

In summary, I would like to inform you that this letter is only a brief summary of the more important findings of this research. If you require further information, a copy of my Masters Thesis can be obtained from Massey University Library in Palmerston North under the following title: *Patients' Perspectives on Fibromyalgia Syndrome (FMS)* by Maggie C. J. Cheng. Thank you for your time and effort.

Regards,

Maggie C.J. Cheng