Assessing Openness To Counselling Referrals And Exploring Patients' Reports Of Who Helps In The Management Of Fibromyalgia

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ABSTRACT

This study explores the openness of people with Fibromyalgia (FM) to counselling referrals, and the issue of who helps in the management of symptoms. Data were collected from 190 support group members using an online survey. Results indicate that 52% of participants believe they would benefit from seeing a counsellor. Further, in 67% of cases, reports of illness distress, emotional and practical problems correctly differentiated those who believed they would benefit from counselling referrals from those who did not. Participants report that health care, community, and interpersonal resources are helpful in the management of symptoms. In conclusion, health care professionals should explore the role of psychosocial factors in illness, and consider the benefits of community and interpersonal resources in the management of FM.

TABLE OF CONTENTS

ABSTRACT	ii
TABLE OF CONTENTS	iii
LIST OF TABLES	. v
LIST OF FIGURES	vi
LIST OF APPENDIXES	vii
ACKNOWLEDGEMENTS	viii
CHAPTER ONE: INTRODUCTION Purpose of this Research	1 5
CHAPTER TWO: LITERATURE REVIEW Gender Differences Biopsychosocial Considerations Physician-Patient Interactions Shared Decision Making Treatment Approaches Multidisciplinary Treatment Behavioural Approaches Cognitive Behavioural Therapy Acceptance and Commitment Therapy Summary Hypotheses Hypothesis 1. Hypothesis 2. Hypothesis 3.	7 7 9 11 14 15 16 20 21 21 23 24 24 24 24
Exploratory questions A. Exploratory questions B.	25 25 25
CHAPTER THREE: METHOD Participants Procedures Measures Demographics The Patient-Doctor Relationship Illness Distress Survey Patient Problem Checklist Willingness to Seek Counselling The Pain Catastrophizing Scale Open-Ended Questions Data Analysis	26 26 27 27 28 28 28 29 29 30 30

CHAPTER FOUR: RESULTS	33
Descriptive Statistics	33
Demographics	33
Health Care Professionals Seen in the Last Four Months	34
Patient Problem Checklist	34
Willingness to Seek Counselling	35
Comparisons between Geographical Areas	36
Analyses of Measures	38
PDRQ-9	38
Illness Distress Survey	39
Emotional Problems	41
Practical Problems	42
Pain Catastrophizing	44
Summary of Analyses of Measures	44
Physicians' Referrals to Counselling and Patients' Ratings of their Physicians	46
Hypothesis 1.	46
Hypothesis 2.	46
Predicting Openness to Counselling Referrals	47
Hypothesis 3.	47
Post hoc exploration.	48
Biopsychosocial Contributions to Illness Distress and Contentment	48
Exploratory questions A	48
Illness Distress.	48
Contentment.	50
Who Helps and How do They Help	51
Exploratory questions B	51
CHAPTER FIVE: DISCUSSION	54
Assessment of NCCN Measures	54
Use of Health Care Resources	56
Physicians' Referrals to Counselling and Patients' Ratings of their Physicians	60
Predicting Openness to Counselling Referrals	61
Biopsychosocial Contributions to Illness Distress and Contentment	63
Other than Health Care Professionals: Who Helps and How	64
Conclusions	66
Limitations	69
Future Research	71
REFERENCES	73

LIST OF TABLES

Table 1: Demographics of Participants $(n = 190)$	33
Table 2: Summary of the Number of Participants who had Accessed Specified Health Care Services Four Months Prior to Completing the Survey	34
Table 3: Summary of the Frequency and Percentage of Practical and Emotional Problems Reported by Participants $(n = 190)$	35
Table 4: Participants Reporting 'Yes' to Questions Assessing Willingness to Seek Counselling	36
Table 5: Comparison of Mean Scores on Variables of Interest by Geographical Area	37
Table 6: Comparing Geographical Areas on Willingness to Seek Counselling	38
Table 7: Two Factor Structure & Pattern Matrix for the Illness Distress Survey using Principal Axis Factoring with Oblique Rotation	41
Table 8: Summary of the Structure and Pattern Matrix of the Practical Problems Checklist using Principle Axis Factoring with Oblique Rotation	43
Table 9: Means and Confidence Intervals Comparing Scores of Those Who Believe they will Benefit from Counselling to Those Who Do Not	47
Table 10: The Bivariate and Partial Correlations of the Predictors with Illness Distress Scores	50
Table 11: The Bivariate and Partial Correlations of the Predictors with Contentment Scores	51

LIST OF FIGURES

Figure 1. Scree plot for the Patient-Doctor Relationship Questionnaire-9	39
Figure 2. Scree plot for the Illness Distress Scale	40
Figure 3. Scree plot for the Emotional Problems Checklist	42
Figure 4. Scree plot for the Practical Problems Checklist	43
Figure 5. Scree plot for the Pain Catastrophizing Scale	44

LIST OF APPENDIXES

APPENDIX A: Ethics Approval	81
APPENDIX B: Initial Contact E-mail, Consent Form, Debriefing Form	83
APPENDIX C: Demographic Information	88
APPENDIX D: Patient-Doctor Relationship Questionnaire-9	90
APPENDIX E: Illness Distress Survey	92
APPENDIX F: Problem Checklists	94
APPENDIX G: Willingness to Seek Counselling	96
APPENDIX H: Pain Catastrophizing Scale	98

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INTRODUCTION

The term Fibromyalgia (FM) was first introduced in 1976 to describe a combination of symptoms that include chronic diffuse pain, non-restorative sleep, and predictable tender points (Boissenvain & McCain, 1991). Symptoms of FM most often appear gradually in adulthood; however, these symptoms can also appear immediately after a physical or emotional trauma. Pain and fatigue can be intermittent but are usually chronic and remain unexplained by laboratory findings. Diagnosis depends upon the individual's reports of pain in both the upper and lower body that persists beyond three months, and non-restorative sleep patterns. Conditions often associated with FM include migraines, Raynaud's syndrome, irritable bowel syndrome, and depression. FM also frequently co-exits with rheumatological conditions such as rheumatoid arthritis, osteoarthritis, and lupus (Boissenvain & McCain, 1991).

Despite efforts made to understand this complex and potentially disabling syndrome, the cause of FM remains unknown (Julien, Goffaux, Arsenault & Marchand, 2005). FM is often approached as a dysfunction in the central nervous system (CNS). However, most people who develop FM do not have a history that would justify increased sensitivity to pain through CNS pathways (Vierck, 2006). In attempts to understand this perplexing syndrome, researchers have explored potential causes including muscle abnormality, sleep disturbance, biochemical metabolism, and immune system dysfunction (Boissenvain & McCain, 1991). Despite interesting findings, results have been inconclusive, and researchers expect that FM likely has multiple causes.

This uncertainty regarding the etiology of FM is a source of distress for patients who feel the reality of their pain complaints are discredited by a lack of objective findings on medical tests (Asbring & Narvanen, 2003). People with FM may believe they are being accused of exaggerating, malingering, or of having a mental health condition rather than a physical health problem (Asbring & Narvanen, 2003). Researchers concur that physicians often attribute FM

symptoms to psychological difficulties or emotional reactions to difficult life circumstances (Woivalin, Krantz, Mantryranta & Ringsberg, 2004). Having a chronic pain condition that is attributed to psychological problems is associated with greater stigma than having a diagnosis of a physical health problem (Thorne, Harris, Mahoney, Con & McGuinness, 2004). Consequently, continuing to search for a physical explanation for this complex and potentially disabling syndrome is a high priority for those whose lives are affected by FM.

FM has become one of the three most common diagnoses to be received by Canadians, with an estimated three to five percent of the population diagnosed with this syndrome (Gran, 2003). Due to the relatively large portion of people diagnosed with this disorder, concerns exist regarding the overuse of this diagnosis to explain complex chronic pain. The practice of relying upon the presence of tender points, common in many patients with various pain problems, may result in improper diagnosis and treatment for those with conditions that have similar symptoms. Wolfe (1995), in his letter to the editor of *Pain*, asserted that patients with musculoskeletal pain deserve a complete and competent physical examination including palpation of individual muscles for tenderness, exploration for possible muscle shortening, evaluation of joint range of motion, and of deep back muscles. Wolfe's (1995) major concern at this time was that patients being unsuccessfully treated for FM may actually be experiencing a pain condition that, if identified, could be more successfully treated.

Moreover, there are concerns that physicians diagnosing people with FM may be disabling people by labeling them with a chronic pain disorder (White, Harth & Teassell, 1995). Concerns of disabling people who meet the diagnostic criteria by providing a FM diagnosis appear to be unfounded, and the distress of not having a label to explain chronic pain can be more detrimental to one's emotional well-being (Madden & Sim, 2006). After receiving a diagnosis of FM, people often experience momentary relief that the suffering they have experienced for years can be labeled (Haugli, Strand & Finset, 2004). However, this relief can quickly fade when they

further discover that the reason for their syndrome is unknown, and available treatments only help to better manage symptoms (Haugli et al., 2004). FM treatments with demonstrated efficacy include tricyclic antidepressants, aerobic exercise, and Cognitive-Behavioural Therapy (CBT) (Bradley, McKendree-Smith & Cianfrini, 2003; Goldenberg, Burckhardt & Crofford, 2004; Theime, Flor & Turk, 2006; Yousefi & Coffey, 2005). However, some people meeting the criteria for FM may encounter physicians who are reluctant to acknowledge the severity of subjective symptoms being reported (Haugli et al., 2004; White et al., 1995) and may receive inadequate care.

Werner and Malterud (2003) concluded that women with FM exert a considerable amount of energy in attempts to be perceived by health care professionals as being in need of care. Confronted by statements that they either appear too well or are too young to be experiencing the symptoms and pain described, women with FM reported attempting to make invisible symptoms noticeable. Efforts to have symptoms validated may be the cause of many repeat and nonproductive physician visits and further can detract from the energy needed to adjust to the challenges of chronic pain.

Kenny (2004) reported that when test results are negative, physicians often conclude that pain exists due to psychological causes. In contrast, patients are more likely to conclude that negative test findings and continuing symptoms are due to the limited ability of the attending physician. Attempts to understand FM symptoms as either physical or psychological are problematic. According to the biopsychosocial model of pain, pain includes interactive sensory, cognitive, and social components (Clark-Callister, 2003). This model supports the contribution of emotional challenges to the pain reports of people with FM. For example, in studies with people who have chronic pain disorders, depression is frequently associated with catastrophic thoughts regarding the meaning of painful symptoms. Catastrophic thinking is defined as: expecting or worrying about major negative consequences, even when the outcome is of minor importance

(Turner et al., 2000). Catastrophizing about pain has been demonstrated to be associated with increased reports of pain intensity, pain behaviours, medication usage, and disability (Sullivan, Martel, Tripp, Savard & Crombez, 2006). Catastrophizing is further associated with a reduction of effective coping strategies, increased feelings of helplessness, pessimism, and increased prevalence of suicide ideation (Edwards, Smith, Kudel & Haythornthwaite, 2006).

To provide effective care for patients with FM, physicians and patients need to develop a therapeutic alliance (Kenny, 2004) where patients are approached as part of the solution and biological, psychological and social factors can be examined in a nonjudgmental fashion. This alliance includes the physician and the patient coming to an understanding regarding the multiple factors contributing to continuing symptoms so that the syndrome can be managed more effectively (Kenny, 2004). Patient-centred care has been identified as the optimal approach in the creation of a therapeutic alliance (Roter, 2000). This approach includes integration of the biomedical model and reality as constructed by the patient (Roter, 2000). The basic components of patient-centred care include: (1) providing quality care within the constraints of the health care system; (2) eliciting the patient's concerns and reasons for visiting; (3) being responsive to the patient's emotional state and concerns; (4) being informative in a manner which is understandable, useful, and motivating; and (5) including the patient in the decision-making and treatment process.

Currently, physician-patient interactions are most often dominated by physicians (Roter, 2000). This may be problematic, considering that Stewart (1995), in a comprehensive literature review, suggests that patient involvement in care is associated with optimal health outcomes including better emotional health and functional status. Conversely, not including patients in care decisions can result in malpractice suits and noncompliance with treatment regimes. Research conducted by Asbring and Narvanen (2002) revealed that women with FM often feel belittled when treatment recommendations include antidepressant medications and/or counselling

resources. With the noted benefits of CBT in the management of pain, finding ways in which physicians can broach this topic with patients, in a manner that will not be perceived by patients as condescending, may be pertinent to improving health outcomes for people with FM. Banez and Gallagher (2006) recommend that physicians refer people with chronic pain problems to psychological care when symptoms are first presented. People who receive a referral only after biomedical interventions have failed tend to be more resistant to the potential benefits of counselling interventions. They further suggest that referral sources present counselling resources as an opportunity to learn the influence of stress and emotions on symptoms, and to become skilled at new ways in which one can cope with pain in order to return to regular activities.

Purpose of this Research

FM is a chronic condition and current interventions are limited to the management of symptoms and promoting self-care (Affleck et al., 2001). People with FM are affected by symptoms that can make daily activities challenging, and by the stigma associated with comorbid psychological diagnoses (Thorne et al., 2004). Patients seeking treatment for pain often expect that physicians will be able to provide an explanation for their conditions and provide suitable treatment (Haugli et al., 2004). Despite the treatments provided for people with FM, symptoms most often persist and become a source of distress for patients and their attending physicians (Wasan, Wootton & Jamison, 2005).

Qualitative researchers suggest that physicians often tell people with FM that their pain is psychological rather than physical (Asbring & Narvanen, 2002; Asbring & Narvanen, 2003; Werner & Malterud, 2003). These studies also show that patients with FM are offended by allegations that emotional factors contribute to their pain experience and therefore, are likely to reject counselling referrals. This research will explore the frequency with which patients recall physicians suggesting that they seek counselling resources, and how this relates to patients' ratings of the patient-physician relationship. Secondly, this research will examine patients' self-

reports of illness distress, emotional problems, and practical problems to examine if scores on these measures can differentiate between patients willing to seek counselling from those who are not.

Allowing patients to assess their own need for counselling support may enhance the therapeutic partnership and prevent the patient from feeling belittled or rejected by a physician who recommends counselling as a way to manage symptoms. If clear differences exist between self-reported problems of patients who are willing to seek counselling versus those who are not, it may be possible to use these measures to predict when patients with FM would be most open to accessing counselling resources. Thirdly, this research will investigate the contributions of pain reports, health care professionals seen in the last four months, pain catastrophizing, and practical problems as predictors of illness distress and contentment. Lastly, this research will investigate patients' reports of who is most helpful in managing FM symptoms, and how others are helpful.

LITERATURE REVIEW

Idiopathic pain refers to complex medical conditions where pain is the primary complaint and subjective reports of pain are in excess to objective medical findings. The socioeconomic impact of FM and other idiopathic pain disorders is exceeded only by cardiovascular disease, and cancer (Almo, Moral & Perula de Torres, 2002). Repeatedly, researchers have found evidence that psychological and social factors contribute to the development and maintenance of chronic pain. However, physicians' approaches to diagnosis and treatment of chronic pain conditions still focus on a biomedical model which rarely yields satisfactory results for patients (Almo et al., 2002, Leventhal, 1999).

FM is one of the most common idiopathic pain disorders and is associated with poor sleep and heightened sensitivity to noxious stimuli (Diatchenko, Nackley, Slade, Fillingim & Maixner, 2006). In order to receive a diagnosis of FM, patients must report experiencing widespread pain for longer than three months, and report pain at 11 out of 18 established tender points (Wolfe et al., 1990). FM symptoms are frequently observed in patients with inflammatory bowel disease, hepatitis C, HIV, Lyme disease, thyroid disorder, diabetes, osteoarthritis, and several rheumatic conditions (Gran, 2003). When FM symptoms are secondary to another disorder, successful treatment of the primary condition can also result in resolution of FM symptoms (Gran, 2003). Conversely, when FM is a primary condition, symptoms most often persist and fluctuate over time despite treatment attempts (Gaston-Johnsson, Gustafsson, Felldin & Sanne, 1990; Gran, 2003).

Gender Differences

Among Canadians, FM is believed to affect approximately 5% of women and 1.5% of men (Rollman & Lautenbacher, 2001). The higher prevalence of FM among women may be due to biological differences. It has been reported that sex hormones influence the experience of pain at various life stages (LeResche, Mancl, Drangsholt, Saunsers & Von Koff, 2005; Granella,

Cavelini, Sandrini, Manzoni & Nappi, 1998). For example, researchers examining the relationship between pubertal developments and pain reports in adolescents found that physical development and gender differences were associated with the experience of chronic pain including stomach aches, muscle and joint pains, and headaches (LeResche et al., 2005). The higher frequency with which pain is reported by females suggests that biological development predisposes women to chronic pain conditions (LeResche et al., 2005).

Social factors may also be influential in the increased prevalence of FM among women (Wijnhoven, de Vet & Picavet, 2006). Rollman and Lauenbacher (2001) report that many women work in environments designed according to male norms and have fewer opportunities for advancement to managerial positions. When women seek care from health care professionals, their injuries are often treated and evaluated differently than those of men. For example, women are more likely than men to have their symptoms attributed to ineffective coping strategies. Furthermore, women may experience greater stressors in private life in comparison to men. Even when women are employed, they are more likely to be expected to take on the role as primary caregiver and homemaker creating additional stressors (Rollman & Lauenbacher, 2001).

Less than 25% of people diagnosed with FM are men (Buskila, Neuman, Alhoashle & Abu-Shakra, 2000; Rollman & Lautenbacher, 2001). Research conducted by Buskila et al. (2000) matched 40 men with FM with 40 women, based on age and education level. Participants completed surveys that assessed pain, anxiety, depression, and quality of life. They were further assessed for the number of tender points and tenderness thresholds. Results indicated that women and men with FM experienced a similar number of tender points with women showing a lower threshold for pain. Despite reporting a greater pain threshold, men with FM generally reported significantly greater current pain levels than women when using a visual analogue scale. Further comparisons revealed that men with FM also reported more fatigue, morning stiffness, depression, sleep problems, and physical impairment than women with this condition. This

research raises questions regarding whether or not the prevalence of FM in males is biased by men's tendency to demonstrate greater pain thresholds despite subjective reports of greater symptom severity, and physical impairment.

Biopsychosocial Considerations

Research supports the conclusion that biological, psychological, and social factors can contribute to the development and maintenance of FM. Many biological causes for FM have been explored; however, no unequivocal conclusion has been reached to explain the etiology and course of this syndrome. Biological explanations include the suggestion that FM is a result of an over-active sympathetic nervous system (Martinez-Lavin, Lopez, Medina & Nava, 2003). Martinez-Laven et al. (2003) explain that a hyperactive sympathetic nervous system can impair the functioning of the central and peripheral nervous systems. The pain that results from this impairment is referred to as neuropathic pain. Neuropathic pain is associated with such complaints as prickling and tingling sensations in the skin, abnormal sensitivity to touch, sudden bursts of pain for no apparent reason, and burning sensations. In comparison to patients with rheumatoid arthritis, who experience pain in relation to joint destruction and inflammation, people with FM are significantly more likely to describe experiencing symptoms of neuropathic pain. Pharmacological researchers have recently begun exploring the benefits of antineuropathic medications to treat FM symptoms. Current pharmacological treatments include opioids, anticonvulsants, and tricyclic antidepressants, and can be successful in decreasing pain by as much as 40% (Turk, 2004). However, biological factors do not fully account for the pain and disability associated with FM, and psychological and social factors need to be considered in the management of this syndrome.

Psychological factors that can influence the perceived severity and maintenance of FM symptoms include fear of pain, pain catastrophizing, and depression (Raphael, Janal, Nayak, Schwartz & Gallagher, 2006; Turk, 2004). Patients often interpret pain symptoms as an indicator

of an underlying disease or an indicator of muscle or joint damage (Turk, 2004). Believing pain is a threat to their well-being, patients may attempt to avoid any activity that they perceive could interfere with healing or exacerbate pain (Turk, 2004). Fear of further injury or re-injury has been found to be the best predictor of reported disability in patients with FM and is also associated with a preoccupation with bodily symptoms (Turk, Robinson & Burwinkle 2004).

Turk et al., (2004), in a study that included 233 female patients, found evidence that there was a high prevalence of fear of pain and activity among women with FM. Those who reported greater fear also reported greater disability. Moreover, fear of pain was a better predictor of disability than reported pain severity, and pain duration. Patients who reported greater fear of pain were also more likely to be diagnosed with a depressive disorder. From a biopsychosocial perspective, fear of pain and activity may result in physical deconditioning which can further contribute to disability.

Pain and disability vary greatly in patients diagnosed with chronic pain problems.

Research done by Turner, Jensen, and Romano (2000) on the variability in patient disability revealed that 8% of disability could be accounted for by age, gender, and pain intensity.

Strikingly, 42% of reported disability and 47% of reported depression was accounted for by beliefs, coping, and catastrophizing. Consistently, people who engage in catastrophic thinking report increased pain intensity and emotional distress (Sullivan, Rodgers & Kirsch, 2001; Turner et al., 2000). Researchers suggest that females are more likely to engage in catastrophic thinking than males (Edwards et al., 2004). Moreover, Edwards et al. (2004) revealed that after controlling for catastrophizing, the gap between men and women in reported pain was eliminated. Catastrophic thinking may be a response to distressing symptoms in combination with lacking adequate support to manage symptoms in addition to one's everyday challenges. Physicians who discredit the patient's pain experience are likely to contribute to the patient's perceived lack of social support and further amplify the distress of personal adversity. To decrease catastrophizing

in a clinical setting, it is recommended that physicians validate the patient's pain and suffering (MacDonald, 2004). Validating the patient's experience can help the patient to feel understood and supported.

Inadequate support in combination with adverse life events may influence the development and maintenance of FM. Anderberg, Marteinsdottir, Theorell and von Knorring (2000) found that depressive and anxious states in relation to negative psychosocial events frequently precede or accompany the onset of FM. More specifically researchers found that, in comparison to healthy control participants, women with FM reported experiencing significantly more negative events during childhood. Further, 80% of women with FM who were surveyed recalled experiencing a significant negative life event before the onset of their FM symptoms. People with FM were also more likely to report currently experiencing life events that included abuse, significant other suffering due to an illness or accident, and financial problems.

McBeth, MacFarlane, and Silman (2002) have found that chronic pain alone does not predict future well-being. They report that life stressors in combination with somatic symptoms, illness behaviours, health anxiety, and fatigue are more likely to predict the impact chronic pain will have on a person's physical and emotional well-being than subjective reports of pain intensity. For example, activity avoidance can result in physical deconditioning and social isolation, ultimately leading to greater distress. Those who become distressed focus more on bodily symptoms and may frequently consult with health care professionals. These findings further support a need to apply a biopsychosocial model in attempts to understand and manage FM.

Physician-Patient Interactions

Physicians and patients tend to have difficulty accepting a health condition that cannot be identified by medical test results. Unique concerns for those with FM in comparison to those with accepted somatic diseases include lack of biomarkers, having pain attributed to psychological

problems, and lack of effective treatments (Madden & Sim, 2006; Thorne et al., 2004). The challenges of diagnosing and treating this syndrome may also result in patients being rejected by health care professionals (Walker, Wayne, Keegan, Gardner & Sullivan, 1997).

The uncertainty around FM and its treatment challenges physicians' professional identity as problems solver and healer. Avoidance, intellectualization, depersonalization, and cutting off are defenses that physicians may use to manage the uncertainty regarding their own professional abilities (Asbring & Narvanen, 2003). Asbring and Narvanen (2003) conducted semi-structured interviews with 26 physicians to investigate how physicians categorized patients with FM, and the strategies physicians used when working with patients who have complex conditions. Results indicated that these physicians distinguished between disease and illness. Diseases were defined as conditions with known biological causes. Illnesses were defined as a condition without objectively measurable criteria. Based on these definitions, FM was identified as an illness. An illness was perceived to be something that could be endured. Moreover, some physicians expressed views that patients with FM had limited experience with symptoms and exaggerated the severity of their problems. Patients with FM were further described by physicians as being people who placed high demands on themselves and others, were illness-fixated, and were pessimistic.

The need for greater support from colleagues and other staff members when working with patients with complicated disorders was also mentioned in this research. Physicians expressed that they had received inadequate medical training to manage patients with complex conditions. Overwhelmed by their own lack of knowledge and by the patients' frustrations, some physicians reported impulsively prescribing medications, ordering further tests, or referring patients to other health care professionals. These actions seemed effective in diffusing patient distress over the short-term, however, did not appear to improve long-term health outcomes. They also described practices that included limiting the number of appointments set aside for

patients with FM during the week, and distributing these patients among physicians at the clinic. Finally, physicians were cautious about discussing psychological aspects of illness with patients due to the assumption that patients would feel humiliated. Asbring and Narvanen (2003) concluded that it was important for physicians to recognize the limitations of the biomedical model, to increase their knowledge about the illness experience, and to have the support of their colleagues when working with patients with FM.

According to Haugli et al. (2004), patients with FM struggled to be given a diagnosis, to be believed, and to escape psychological explanations for their physical symptoms. Research on chronic illness suggests that diagnosis can play a crucial role in providing patients with an explanation that aids in understanding symptoms, and providing insight into the direction they must take to regain control of their health (Madden & Sim, 2006). Patients with FM are often uncertain about their diagnosis, and the information they are provided may not match with their previous understanding of illness. Diagnosis without an explanation to match the patient's understanding of symptoms can enhance illness uncertainty and result in excessive help-seeking behaviours (Madden & Sim, 2006).

Madden and Sim (2006) state that physicians often lack adequate information to help patients with FM understand the meaning of their symptoms. Lack of information prevents patients from being able to explain their condition to significant others. Patients, unable to explain their conditions, may struggle to gain appropriate support from family, friends, and coworkers. Further, provided with inadequate information, patients must make individual efforts to understand and define the parameters of their illness. Without clearly delineated parameters, FM can quickly become a meaningless label attached to a variety of unpredictable and threatening symptoms.

Madden and Sim (2006) additionally report that patients, in attempts to understand their symptoms, use common sense beliefs to explain the etiology of their chronic pain. Often patients'

explanations for the cause of their chronic symptoms include past physical trauma and negative emotional events. Creating their own explanation for the onset of FM may give meaning to their symptoms. Physicians who accept the patients' explanation may be influential in facilitating adjustment to chronic pain and fatigue. Conversely, physicians who inappropriately adapt their definition of FM to explain all future symptom complaints can undermine their own credibility and encourage help-seeking behaviours. Physicians who are uncomfortable with emotions and discourage sharing also may negatively influence patients' behaviours. By recognizing their role in frustrating patient interactions, physicians may be better able to work with the patients they identify as 'difficult' (Walker et al., 1997).

Physicians should be aware that patients with FM may be vulnerable to misunderstandings and communication breakdowns due to skepticism regarding the reality of their syndrome (Thorne et al., 2004). Working effectively with patients who have a history of difficult interactions with health care professionals may require advanced communication skills training. Effective patient-physician communication has been found to be associated with better health outcomes (Stewart, 1995). Aspects of effective communication include clear information being provided to the patient, reaching agreements regarding diagnosis and treatment, patient participation in the decision-making process, and a communication style that incorporates empathy, support, and positive affect (Almo et al., 2002). This approach is referred to as 'Patient-centered care' and researchers have demonstrated the benefits of using this approach in consultation (Almo et al., 2002).

Shared Decision Making

Shared decision-making is a pivotal component of patient-centred care. Physicians who incorporate shared decision-making into their practice report less frustration and greater positive regard for their patients (Bieber et al., 2006). Bieber et al. (2006) write that patients engaging in the decision-making process report preferring this approach over other interaction styles, and

consistently rate the quality of their physician visits as more satisfactory than those who merely receive information. Interestingly, most patients with FM, regardless of the approach used, will report that their treatment was successful despite continuing symptoms. Therefore, shared decision making may enhance the therapeutic relationships and improve coping, but may not result in decreased symptoms. Moreover, it can be difficult to engage some patients in a shared decision making process. Barriers to shared decision making include: patients wanting the physician to make the decision, patients quickly agreeing to the physician's suggestions, time management, and poor communication skills. Improving physicians' communication skills may be necessary to effectively incorporate shared decision making into clinical practice.

Patients report believing that the relationships they have with their doctors are important in the care they receive (Haugli et al., 2004). Therefore, patients who perceive their physicians to be unsupportive may seek help from additional care professionals. Avoiding communication styles that may be perceived as judgmental and validating the patient's efforts to manage a complex illness may foster a better therapeutic relationship (Thorne et al., 2004). Further, exploring patients' understandings of their symptoms, and providing patients with information about traditional and alternative treatments are strategies patients identify as supportive (Haugli et al., 2004). Physician support in searching for an appropriate diagnosis and illness management strategies may facilitate adjustment to chronic pain and fatigue (Madden & Sim, 2006). This includes being aware of other health care resources with the potential to assist those with FM. Patients, challenged by continuing symptoms will likely seek referrals to other health care professionals in hopes of returning to their previous health status (Sim & Adams, 2003).

Awareness of the researched benefits of alternative therapies, exercise, and CBT may prepare physicians to provide patients with information regarding treatment options and appropriate referrals.

Treatment Approaches

Many health care professionals can play a role in helping patients with FM better manage their symptoms. It should be noted that different health care professionals may disagree on what the primary problem is for patients with FM. Sim and Adams (2003) found that physiotherapists reported pain was the main problem, while occupational therapists believed fatigue was the chief concern. Treatment objectives of occupational and physiotherapists also differed. The treatment objectives of physiotherapists included increasing exercise tolerance and fitness, reducing pain, and improving functional ability. The treatment focus of occupational therapists included increasing functional activities, improving the management of fatigue and pain, and assisting in the development of relaxation skills. Despite these differences, both groups agreed that patients with FM were moderately responsive to occupational and physiotherapy, and that psychosocial factors play a key role in patients' treatment outcomes. Health care professionals further agreed that, in most cases, patients are not adequately informed about their condition and that psychological factors need to be addressed when treating patients with FM.

Multidisciplinary Treatment

Observations reported by health care professionals suggest that a multidisciplinary approach is essential to achieve optimal outcomes for patients with FM and should include: good rapport with the patient, education of the patient and family, early diagnosis and appropriate referrals, a positive attitude, and psychological support (Sim & Adams, 2003). However, very few patients with FM are given the opportunity to take part in multidisciplinary treatment programs (Bondegaard-Thomsen, Sorensen, Sjogren & Eriksen, 2001). Multidisciplinary treatment programs are usually only offered after all other procedures have failed (Bondegaard-Thomsen et al., 2001).

Angst, Brioschi, Main, Lehmann, and Aeschlimann (2006) conducted a study examining the benefits of a multidisciplinary treatment program for patients with chronic pain. Sixty-five

percent of the patients had a diagnosis of FM, and the remaining participants had chronic back pain. Only a small portion of participants were men, and no comparisons between male and female treatment outcomes were reported. This study was not randomized and only included patients willing to learn behavioural patterns, motivated to participate in a graded exercise program, and deemed to have the ability to formulate realistic functional goals. The intervention used in this research was a four week inpatient program and included daily sessions of active physiotherapy, aerobic endurance training, individual psychotherapy, Quigong, creative activities, relaxation therapy, education, medical consultation and pharmacotherapy. At the termination of treatment, use of analgesics had decreased and use of antidepressants increased. Patients with FM and back pain showed similar and significant improvements on measures of physical and emotional health. These improvements were maintained at three and six month follow-up.

It is expected that the effectiveness observed within this study was largely due to participants being highly motivated to take part in improving their health. Researchers concluded that unmotivated patients were unlikely to benefit from similar treatment approaches that require a willingness to actively learn and apply adaptive coping strategies. Other concerns regarding applying this approach to the treatment of chronic pain includes the intense inpatient treatment process that consumes a month of patients' lives, and the high cost. A closer examination of the costs and benefits of individual and varied combinations of interventions used within this study could be further explored to determine whether less costly and time demanding interventions can effectively improve health outcomes for patients with FM.

Multidisciplinary treatments are most frequently recommended for people with FM when symptoms result in being absent from work (Skouen, Grasdal & Haldorsen, 2006). Therefore, it is likely that some patients are less motivated than those who took part in the study conducted by Angst et al. (2006). Skouen et al. (2006) conducted a randomized trial that included a sub-sample

of 215 patients with chronic wide spread pain who had been off work for a minimum of eight weeks due to their symptoms. Patients were randomized to receive (1) treatment as usual, (2) light treatment, or (3) extensive treatment. 'Treatment as usual' included patients being sent back to their general practitioners. Treatment given by general practitioners to patients with chronic wide spread pain may consist of pain medications, anti-depressants, referrals to physiotherapists, or referrals to chiropractors. Data revealed that, of patients sent back to their physicians, 50% were referred to physiotherapy, and 20% had tried an alternative therapy.

Patients assigned to 'light multidisciplinary treatment' had one hour with a physiotherapist, 30 to 60 minutes with a nurse, an assessment by a psychologist, a one hour education session on anatomy, pain, exercise training and lifestyle, and 15 minutes of feedback from the treatment team that emphasized reduction of fear, and coping strategies. Antidepressants were prescribed when deemed necessary, and patients were encouraged to reduce their use of analgesics. Patients further received an individually tailored exercise program and were offered individual follow-up appointments with the team at three and 10 months.

The 'extensive multidisciplinary treatment program' lasted for four weeks, and consisted of six hour sessions five days each week. The daily program consisted of cognitive coping strategies, advice, education, exercise, and the occasional workplace interventions. If necessary, antidepressants were prescribed, minimal use of analgesics was encouraged, and daily exercise was supervised. Result of this study indicated significant differences between men and women in response to treatment. For the first months after treatment women from the extensive treatment group reported significantly less days absent from work than those who had received treatment as usual. Men, conversely, showed no benefits regardless of what treatment they received.

Moreover, men taking part in the light treatment group were absent from work more days than those who had received treatment as usual or extensive treatment. Researchers concluded that multidisciplinary programs demonstrate short-term improvements in outcomes for women with

chronic pain, but not for men. Over the long-term differences between groups diminished, suggesting occasional meetings may be required to reinforce the skills learned and to maintain positive lifestyle changes.

Further, women may benefit more from group-based multidisciplinary treatment programs than men because they tend to appreciate group discussion and social support more than men. Moreover, men may be more reluctant than women to acknowledge the influence of relationships, anxiety, and coping on pain and disability. The results of this study, conducted by Skouen et al. (2006), support the likelihood of gender differences in understanding and managing chronic pain. Awareness of these gender differences in adjusting to chronic conditions requires further exploration and may be a consideration when designing multidisciplinary treatment programs for individuals with FM.

Nielson & Jensen (2004) conducted research on the benefits of a multidisciplinary treatment program designed specifically for people with FM. The treatment targeted patients' beliefs and coping strategies, and assessed reports of pain severity, activity level, emotional distress, and life interference as outcome measures. The treatment took place over four weeks in an outpatient program and included physical and occupational therapy, CBT, pain education, and the tapering of pain medications. Researchers found changes in beliefs and coping strategies predicted (1) an increased sense of control over pain, (2) a belief that one is not necessarily disabled by FM, (3) a belief that pain is not necessarily an indicator of damage, (4) decreased guarding, (5) increased activity, (6) seeking support from others, (7) activity pacing, and (8) use of coping self-statements. Researchers concluded that beliefs about the symptoms of FM and adaptive coping strategies should be the target of interventions for people with this syndrome.

Most studies on the treatment of FM include a large portion of middle-age, Caucasian females. Based on this research, it is believed that multidisciplinary treatment approaches that included antidepressant medication, graded exercise programs, and CBT are superior to unimodal

approaches to symptom management. However, access to multidisciplinary treatment programs may be limited due to availability and affordability of health care resources. With consideration of individual and community resources, it may be possible for physicians to orchestrate individualized multidisciplinary treatment programs by providing appropriate referrals, setting goals, and monitoring patients' progress in follow-up appointments.

Living with chronic pain and fatigue is a major challenge to the maintenance of quality of life. Those able to set, pursue, and achieve personally meaningful goals are more likely to successfully adapt to the chronic challenges of FM (Affleck et al., 2001). Affleck et al. (2001) have found that fitness goals of people with FM are often interrupted by pain and fatigue. Interpersonal goals, such as spending more time with family, being less critical of others, and saying 'no' when asked to do favors, were less likely to be disrupted by fluctuations in symptoms and were further associated with improvements in positive mood throughout the day. With this in mind, it may be important for physicians to include both interpersonal, and fitness goals when creating a treatment plan with patients who have FM.

Challenges physicians may face when developing individualized plans include the stigma associated with the use of antidepressant medications and counselling. Patients with FM may be sensitive to the stigma of having their pain and fatigue associated with a psychological rather than a physical condition. Therefore, Banez and Gallagher (2006) suggest that referral sources should present counselling resources as an opportunity to become skilled at new ways to cope with pain in order to return to regular activities.

Behavioural Approaches

There are three researched behavioral approaches believed to be beneficial in the management of chronic pain: Operant Behavioural Therapy (OBT), CBT, and Acceptance and Commitment Therapy (ACT). CBT and ACT incorporate similar techniques used in OBT but take different approaches to cognition and emotion. ACT focuses on the development of

willingness to experience distressing thoughts and feelings so that personally valued goals can be pursued despite chronic pain. Alternatively, CBT focuses on direct efforts to predict and manage pain, and unwanted thoughts.

Cognitive Behavioural Therapy

Bradley et al. (2003) write that there are four essential components of CBT interventions (1) education, (2) skills acquisition, (3) cognitive and behavioural rehearsal, and (4) generalization and maintenance. During the education component a rationale for the therapeutic approach is provided to the patient and close family members. The therapist attempts to gain the active participation of all involved, and begins to alter negative beliefs regarding patients' abilities to manage symptoms and psychosocial challenges. The purpose of skills acquisition is to help those involved learn new cognitions and behaviours that will help individuals better cope with their symptoms and improve their functional ability. Cognitive-behavioural rehearsal creates an opportunity for patients to practice engaging in new thoughts and behaviours. Finally, generalization and maintenance is intended to help patients identify high-risk situations where they are most likely to relapse into old and unhelpful ways of thinking and behaving. Those involved are taught to identify early signs of relapse and rehearse skills to respond to these situations. It is also important to provide patients with evidence of their achievements. This reinforces their ability to actively manage their pain or psychosocial problems.

Closer investigations of the benefits of active strategies to control pain, conducted by Viane et al. (2003), have revealed that the CBT approaches may be effective for patients with mild or moderate pain, but not for those with high intensity pain. Moreover, in some cases, attempts to control uncontrollable events may result in further distress and may be a contributing factor in the development of depressive symptoms. As an alternative to CBT, ACT suggest that adjustment to chronic conditions can be achieved by abandoning the struggle to eliminate pain and redirecting one's energy toward living a valued life with pain.

Acceptance and Commitment Therapy

Acceptance of pain has been shown to be a predictor of better mental health, increased physical well-being, decreased catastrophizing, and lower reports of pain for diverse pain populations including patients with FM (Viane et al., 2003). This approach to treating chronic pain is based on a belief that suffering arises from a combination of the experience of chronic pain, the meaning given to the pain experience, and from struggling and failing to control the pain (McCracken, Vowles & Eccleston, 2005). Encouraging acceptance, rather than teaching strategies that ultimately do not eliminate symptoms, may be an effective approach to helping patients with FM adjust to chronic pain and other symptoms that continue despite medical treatments (McCracken et al., 2005).

McCracken et al. (2005) examined the benefits of multidisciplinary treatment that include physical therapy and ACT. Treatment took part over a three to four week residential program or a three week hospital based program, depending on the needs of the patient. Aspects of psychological treatment included: addressing health behaviours, choosing a personally meaningful direction, enhancing awareness of strategies used to control symptoms, assessing the effectiveness of these strategies, habit reversal training, mindfulness meditation exercises, relaxation exercises, activity enjoyment with pain present, and an exercise to raise awareness of the social effects of overt pain expression. Patients attended a psychological session and a relaxation session daily. Results at three month follow-up showed significant improvements in mood, physical ability, work status, and decreased use of medications.

The effectiveness of behavioural approaches in decreasing disability does not indicate that FM is a psychological condition (Turk, 2004). Even after a psychological intervention, the symptoms of FM are likely to continue. Despite the continuation of symptoms, taking part in CBT or ACT can enhance patients' abilities to manage challenging symptoms. Better symptom management is expected to improve patients' emotional and physical well-being.

In order for psychological approaches to be effective patients must: (1) accept the psychological factors can contribute to symptoms, (2) believe that counselling will help, and (3) be active participants in change. Patients with physicians who explain FM using a biopsychosocial model may broaden the patients' understanding of illness and encourage patient involvement in the treatment process. Finally, not all patients with FM require counselling (McBeth et al, 2002). Inappropriate referrals to counselling resources may be offensive to patients and are likely to be nonproductive. Assessing patients with FM for co-existing emotional, financial, and interpersonal problems may allow for appropriate referrals to counselling to be made by attending physicians.

Summary

Fibromyalgia is a chronic pain condition with an unknown etiology. It is likely that biological, psychological, and social factors contribute to the development and maintenance of this condition (Turk, 2004). FM affects three to five percent of the Canadian population and is four to five times more likely to be diagnosed in women than men (Rollman & Lautenbacher, 2001). Due to the lack of biomedical markers and effective treatments, the relationships between physicians and patients are often strained (Haugli et al., 2004). Physicians many perceive patients to be illness-fixated, and patients may perceive physicians to be uncaring or inadequately informed (Asbring & Narvanen, 2003; Werner & Malterud, 2003). Using a patient-centred approach when working with patients with FM has been shown to improve the therapeutic relationship and may reduce help seeking behaviours (Almo et al., 2002). Patient-centered care includes involving the patient in the decision making process. This process includes physicians informing patients on the potential benefits of available treatments and patients deciding which treatments approaches to use (Bieber et al., 2006). Based on the assessed challenges of individual patients, treatment approaches may include medication, active physiotherapy, and counselling; all

of which have been found to be effective in improving patient outcomes (Clauw & Crofford, 2003).

Of these approaches, counselling may be the most difficult for physicians to recommend to their patients. Research suggests that patients are often offended by referrals to counselling because it infers symptoms are psychological rather than physical in nature (Asbring & Narvanen, 2003; Werner & Malterud, 2003). From a biopsychosocial perspective, all health conditions are multidimensional and therefore can benefit from a varied treatment approach.

Assessing patients with FM from a biopsychosocial perspective would require that physicians go beyond physical symptoms and assess patients for emotional problems, general life challenges, and the impact FM is having on their lives. This information may provide physicians and patients with information regarding whether or not the patient is likely to benefit from a referral to counselling.

Hypotheses

The first two hypotheses examine the impact of counselling referrals on patients' ratings of the patient-doctor relationship.

Hypothesis 1. Research suggests that people with FM will be offended by physicians who suggest they seek psychological care (Asbring & Narvanen, 2002; Asbring & Narvanen, 2003; Werner & Malterud, 2003). Based on previous qualitative research, I predicted that those who reported their physicians had suggested they receive counselling would rate their physicians lower on the Patient-Doctor Relationship questionnaire (PDRQ-9).

Hypothesis 2. Research also suggests that if there is agreement between physicians and patients regarding the need for counselling, ratings of the therapeutic partnership will be enhanced (Sewitch, Abrahamowics, Dobkin, & Tamblyn, 2002). Therefore, patients who are referred to counselling and believe they will benefit from counselling, and those who believe they do not require counselling and are not referred, are expected to rate the quality of their

relationships with their physicians higher than those who appear to disagree with their physicians.

Hypothesis 3. People with FM may attempt to avoid reporting highly on measures of emotional distress to prevent being stigmatized by a psychological diagnosis that may discredit their experience of pain. Looper and Kirmayer (2004) found that patients with FM do not report experiencing greater stigma than those diagnosed with rheumatoid arthritis. Rather, both patient groups report greater stigma due to a diagnosis of co-morbid depression (Looper & Kirmayer, 2004). Despite possible concerns of stigmatization, it was hypothesized that self-reported scores of illness related distress, practical problems, and emotional problems would predict which participants would report believing they would benefit from counselling.

Exploratory questions A. Based on a biopsychosocial model of FM, I examined biological, cognitive and social factors in regards to their contribution to illness distress and contentment with current life situation reported by this sample of patients with FM. Due to the method used to collect data, I was limited to the use of subjective pain reports and reported comorbid conditions as biological factors; pain catastrophizing and emotional problems as cognitive factors; and health care professionals seen in the last four months and practical problems as social factors to predict (1) illness distress and (2) contentment with one's current life situation.

Exploratory questions B. Lastly, I investigated patients' reports of who is most helpful in managing FM symptoms, and in what ways those identified are helpful. Though the contributions of health care professions are believed to be pivotal in the treatment of acute conditions, it is possible that nonprofessionals will be frequently identified as 'most helpful' in the management of chronic conditions that are managed on a daily basis rather than cured. Understanding who is helpful, and how others help in the management of FM, may be important for professionals facilitating the development of support networks for people with FM.

METHOD

Participants

Data from 190 participants were collected between the dates of February 09, 2006 and April 24, 2006. Inclusion criteria included that participants have a physician's diagnosis of FM, and were over the age of 18 years. I e-mailed invitations to over two-hundred potential participants to take part in the study. Participants were sought through support groups listed online, and through an established contact list. The list of community support groups was found on a website created to assist people with FM. This site included e-mail addresses of community support group leaders in the United States, Canada, and the United Kingdom. To protect the identity of participants, the website where contact information was found will not be identified. After receiving an invitation to take part in the study, some of the support group leaders contacted me to inform me they had shared their invitation to take part in the study with members of their support groups. The established contact list contained names and e-mail addresses of 34 people with FM who had previously taken part in a study I had conducted, and included people with FM from Canada, the United States, and the United Kingdom. These participants had completed an internet survey on health consultations and had contacted me requesting the results of the previous study, or to ask questions.

Procedures

Participants were contacted by e-mail (Appendix B) and received a link to an online survey. Online participation allowed for completion of the survey at a time and location that was convenient for participants. The first page of the survey contained a consent form that included a brief explanation of the study, inclusion criteria, notice of potential risks/benefits and a statement of confidentiality (Appendix B). Measures in the survey included the Patient-Doctor Relationship Questionnaire-9 (PDRQ-9) (Ven der Feltz-Cornelis, 2004), the Illness Distress Survey and the Patient Problem Checklist (National Comprehensive Cancer Networks, 2005), the Willingness to

Seek Counselling Checklist, and the Pain Catastrophizing Scale (Sullivan, Bishop & Pivik, 1995). Participants were also asked to provide brief open-ended responses to: who is most helpful in managing your FM symptoms, and how does that person help.

Participants were informed, by completing the survey they were consenting to take part in the study. To decrease the likelihood of participants completing the survey more than once, computer identification numbers were tracked and no gratuity was offered for taking part in the study. On the last page of the survey was a debriefing form (Appendix B) that included a brief version of the research hypotheses, researcher's contact information, and available resources. The final page of the survey also allowed participants a final opportunity to withdraw from the study.

Measures

Demographics

Demographics information (Appendix C) collected included age, gender, ethnicity, education, employment status, and income bracket. To establish a picture of participants' current health and subjective well-being, information regarding health status was collected including: years with FM symptoms, years with FM diagnosis, concurrent illnesses, and types of health care professionals seen in the last four months.

Participants were also asked about their average pain level over the past month (see Appendix C). Pain ratings on a scale from 1 to 10 are commonly used in clinical practice to determine variations in the intensity of pain experienced by an individual. It is believed that an increase or decrease in an individual's pain report consistently reflects an increase or decrease in his or her pain (Downie et al., 1978). Contentment ratings were also assessed on a scale from 1 to 10 (see Appendix C). Some researchers suggest that people can be content despite pain (McCracken et al., 2005), in which case, contentment levels reported may be a better indicator of well-being than reported pain. To assess contentment I asked participants to respond to only one question: "How content are you with your current life situation?" Asking only one question

leaves the meaning of contentment open to individual interpretation. This seemed appropriate since what constitutes contentment can vary among individuals (Fredrickson, 1998).

The Patient-Doctor Relationship

The PDRQ-9 (Ven der Feltz-Cornelis, 2004) (Appendix D) was used to assess the quality of the doctor-patient relationship. The PDRQ-9 is reliable and brief measures created to assess patients' perceptions of their physicians as empathetic and available. Tested with a sample of 165 patients, the coefficient alpha for the scale was .94 demonstrating good internal consistency.

Test-retest reliability was further examined in a sub-sample that volunteered to complete the survey a second time. Participants' scores over a two-month period were similar, supporting test-retest reliability of the PDRQ-9. Construct validity was demonstrated by assessing the scales' ability to discern between patient groups. Authors compared mean scores on the scale between a sample of 110 primary care patients and 55 patients from an epilepsy clinic. Comparison revealed significant differences between patient groups in support of the construct validity of the PDRQ-9.

Illness Distress Survey

The Illness Distress Survey (Appendix E) was a revised version of the National Comprehensive Cancer Networks (NCCN) assessment for patients with cancer (NCCN, 2005). This questionnaire was created to help patients with cancer self-assess whether counselling could be beneficial in helping manage their illness and current life challenges. The site advises those using the scale that scores of four or higher, on a five-point Likert type scale, indicates that support from counselling resources may be beneficial. I modified questions by removing the word 'cancer' and replacing it with 'fibromyalgia'. The validity and reliability for the original and modified version of this survey are unknown.

Patient Problem Checklist

The problem checklist (Appendix F) is a modified self-assessment measure from the NCCN (2005) website. As presented on the NCCN website, I chose to include dichotomous

scales looking at the presence or absence of practical problems (including family problems), and emotional problems. I further added problems with parents to the practical problem checklist because I expected that many participants would be between the ages of forty and sixty years and may be caring for their elderly parents. I did not include the physical problem checklist in this study because it seemed likely many of the items that applied to people undergoing cancer treatment would not apply to people with FM. The validity and reliability of assessing problems in this manner is unknown.

Willingness to Seek Counselling

In order to measure patient's willingness to seek counselling (Appendix G), I asked five questions: (1) has your doctor ever suggested that you might benefit from seeing a counsellor; (2) do you think you would benefit from seeing a counsellor; (3) have you ever seen a counsellor to help you with your fibromyalgia; (4) was seeing counsellor helpful; and (5) could you afford to see a counsellor if you wanted to? Patients responded 'yes' or 'no' to each question with an additional option of 'not applicable' to respond to whether or not seeing a counsellor had been helpful. The reliability of assessing participants' willingness to seek counselling this way has not been assessed.

The Pain Catastrophizing Scale

Sullivan et al. (1995) have found that the Pain Catastrophizing Scale (Appendix H) is a valid and reliable measure for assessing catastrophic thinking about pain. Tested with a sample of 438 first year psychology students, the coefficient alpha for the overall scale was .87 demonstrating good internal consistency. Principal component analysis further revealed that the pain catastrophizing scale contains three subscales including: rumination, magnification, and helplessness. Rumination refers to thoughts being constantly focused on pain; magnification refers to thoughts of the pain becoming worse, or something serious happening due to the pain being experienced; and helplessness refers to thoughts of the pain being overwhelming and never

ending. Rumination, magnification and helplessness are believed to be separate but strongly related components of pain catastrophizing. Finally, construct validity was tested under three scenarios with three different samples of participants including one patient sample. As predicted, responses on the pain catastrophizing were correlated with pain reports and fear of pain thus, supporting construct validity.

Open-Ended Questions

Participants were also asked to respond in writing to two open-ended questions: (1) Who is most helpful in managing your FM symptoms, and (2) How is that person helpful? Due to the chronic nature of FM, it is expected that people with this syndrome access the support of nonprofessionals and, for a variety of reasons, these nonprofessionals may be perceived to be more helpful in the management of FM symptoms. Open-ended questions allow for a more varied response by not limiting participants' responses to predetermined choices. For some participants, the room provided to respond appeared inadequate, as written responses were terminated in mid-sentence.

Data Analysis

Descriptive statistics for demographic information are reported in tables and include frequencies and percents for nonparametric data, and means and standard deviations for parametric data. The frequencies with which participants report specific practical problems and emotional problems are reported along with the frequency with which participants report doctors recommending counsellors; participants believing they would benefit from counselling; seeing a counsellor in the past; seeing a counsellor was helpful; and whether they could afford to see a counsellor. Furthermore, preliminary analyses have been conducted to assess the appropriateness of measures used in this study. More specifically, factor analysis with oblique rotation and reliability analysis were conducted to assess the validity and reliability of measures used. Scree plots and eigenvalues were examined to determine whether constructs were one-dimensional.

When scree plots indicated more than one factor, items were required to meet a set criterion of factor loadings on the structure matrix \geq .30 to be considered part of the overall construct. The structure matrix represents the variance in a measured variable explained by a factor on unique and common contribution basis (Garson, 1998a). The pattern matrix was also reported when scree plots indicated more than one dimension. The pattern matrix contains coefficients representing the unique contribution made by each item to the factor after accounting for the overlap with other factors (Garson, 1998a).

Analysis of variance (ANOVA) was used to assess for significant differences between the mean PDRQ-9 scores of patients who recalled their physicians recommending counselling versus those who reported their physicians did not recommend counselling. ANOVA was also used to assess the differences between mean scores on the PDRQ-9 between patients who appeared to be in agreement with physicians regarding the need for counselling versus those who appear to be in disagreement with their physicians. Assumptions underlying ANOVA include: (1) the dependent variable is normally distributed for each group, and (2) the variances of the dependent variable are similar for each group being examined (Green & Salkind, 2004). Before conducting an ANOVA, preliminary analysis were conducted to ensure the basic assumptions were met.

Discriminant analysis was used to assess whether or not scores on the Illness Distress Survey, Practical Problem Checklist, and Emotional Problems Checklist can discriminate between participants who believe they would benefit from counselling from those who do not. Assumptions underlying discriminant analysis include (1) normal distribution of predictor variables, (2) linearity, and (3) homogeneity of variance (Tabachnick & Fidell, 2007). Before conducting this analysis, preliminary analyses were conducted to ensure basic assumptions were met.

Two linear multiple regression analyses were conducted to assess the contribution of subjective pain reports, concurrent health conditions, pain catastrophizing, emotional problems,

health care professionals seen in the last four months, and practical problems to predict levels of (1) illness distress and (2) contentment with one's current life situation. Before conducting regression analyses, preliminary analyses were conducted to ensure data met the assumptions of a random effects model including: (1) the variables are multivariately normally distributed in the sample, and (2) the absence of singularity and multicollinearity among independent variables (Tabachnick & Fidell, 2007).

A qualitative descriptive approach, as outlined by Sandelowski (2000), was employed to analyze and present responses to open-ended questions. This approach is guided by the principles of naturalistic inquiry and is well-suited for providing candid answers to questions of relevance to health care professionals and policy makers. Similar to quantitative descriptive analysis, qualitative descriptive analysis includes counting responses and the number of participants in each response category; however, in qualitative analysis, further effort is put forth to understand the latent content beyond the surface of existing responses.

RESULTS

Descriptive Statistics

Demographics

The majority of participants in this study were married (62%), were Caucasian (93%), were female (97%), and were living in the USA (85%). Participants were between the ages of 22 to 80 (M = 49.19, SD = 10.68). Only one participant had not graduated from high school, 40% reported some college or trade school, while 41% reported having a bachelor's degree or higher level of education. Thirty-nine percent of participants reported being employed either part or fulltime. Of those who report they were not engaging in paid labour, half reported receiving disability benefits. Fifty-seven percent of all participants reported an income less than 29 999 US dollars. This may indicate that the majority of participants would have difficulty accessing health care resources not covered by their medical insurance. For a detailed summary of participants' demographics see Table 1.

Table 1

Demographics of Participants (n = 190)

	\overline{f}	%		\overline{f}	%
Gender			Race		
Female	184	96.8	Caucasian	176	92.6
Male	6	3.2	Black	2	1.1
			Aboriginal	1	0.5
Education			Hispanic	3	1.6
MD	1	0.5	Mixed	3	1.6
PhD	3	1.6	Other	5	2.6
Masters	22	11.6	Marital Status		
BA/BSc	54	28.4	Single	29	15.3
Diploma	11	5.8	Common law	10	5.3
Some College/Trade School	75	39.5	Married	118	62.1
Graduated	11	5.8	Separated	4	2.1
Did Not Graduate	1	0.5	Divorced	26	13.7
Other	12	6.3	Widowed	3	1.6

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Tuoto communu ji oni pi orioma						
	f	%		f	%	
Income (dollars)			Occupational Status			
0-9 999	43	22.6	Employed (FT, PT)	74	38.9	
10 000-19 999	35	18.4	Unemployed	10	5.3	
20 000-29 999	31	16.3	Homemaker	15	7.9	
30 000-39 999	22	11.6	Retired	25	13.2	
40 000-49 999	18	9.5	On Disability	. 58	30.5	
50 000-or More	41	21.6	Student	8	4.2	
Country			_			
Canada	11	5.8	_	M	SD	
United States of America	161	84.7	Years with symptoms	14.97	10.60	
United Kingdom	18	9.4	Years with FM diagnosis	7.78	5.61	

Health Care Professionals Seen in the Last Four Months

The majority of participants (85%) reported having at least one concurrent condition. Common conditions reported include arthritis, chronic fatigue syndrome, thyroid disorders, asthma, high blood pressure, irritable bowel syndrome, and depression. Fifty-three percent of participants reported accessing three or more health care resources during the four months prior to completing the survey (M = 2.9, SD = 1.5, Mode = 2). For a summary of health care professionals seen in the four months prior to completing the survey, see Table 2.

Table 2
Summary of the Number of Participants who had Accessed Specified Health Care Services Four Months Prior to Completing the Survey

(n=190)	f	%		\overline{f}	%
Doctor (GP)	151	79.5	Pain Clinic	24	12.6
Doctor (Specialist)	121	63.7	Psychologist/Counsellor	46	24.2
Physiotherapist	28	14.7	Acupuncturist	18	9.5
Occupational Therapist	20	10.5	Social Worker	10	5.3
Massage Therapist	42	22.1	Dietitian	4	2.1
Chiropractor	34	17.9	Naturopath	13	6.8
-			Other	35	18.4

Patient Problem Checklist

On average participants scored a mean of 2.19 on the Practical Problem Checklist (SD = 1.8, Mode = 2) and a mean of 5.35 on the Emotional Problems Checklist (SD = 2.43, Mode = 8).

Frequently endorsed practical problems included work/school (42%), insurance (37%), and dealing with their partners (36%). Emotional problems most frequently endorsed included fatigue (96%), worry (77%), and sadness (73%). For a complete summary of problems reported see Table 3.

Table 3

Summary of the Frequency and Percentage of Practical and Emotional Problems Reported by Participants (n = 190)

Practical Problems	\overline{f}	%	Emotional Problems	f	%
Housing	45	23.7	Worry	146	76.8
Insurance	70	36.8	Fears	118	62.1
Work/School	77	40.5	Sadness	139	73.2
Transportation	55	28.9	Depression	114	60.0
Child Care	7	3.7	Nervousness	103	54.2
Dealing with Children	53	27.9	Loss of Interest in Activities	112	58.9
Dealing with Partner	69	36.3	Anger	102	53.7
Dealing with Parents	41	21.6	Fatigue	182	95.8
Reported No Practical Problems	39	20.5	Reported No Emotional Problems	4	2.1

Willingness to Seek Counselling

In 37% of cases, physicians had made counselling referral and the patient agreed that they would benefit from these referrals. In 14% of cases, physicians had recommended counselling and patients did not agree that counselling would be helpful. Conversely, 15% of participants in this study reported believing counselling could be helpful and did not recall their physician suggesting counselling. Finally, in 34% of cases, participants reported that their physician had not suggested counselling and they agreed counselling would not be beneficial. Results indicate that the larger portion of participants in this study appeared to be in agreement with their physicians regarding whether or not they would benefit from a referral to counselling resources (roughly 71%).

Of those participants who reported believing counselling would not be helpful, 33% had seen a counsellor or a psychologist before, and 40% reported that the counselling they received had been helpful. Conversely, of those who reported believing counselling would be helpful, 42% had seen a psychologist before and, of those, 86% reported that seeing a counsellor or psychologist was helpful. Finally, 56% of patients who reported believing a counsellor or psychologist would be helpful reported that they could not afford to see a counsellor. In fact, in 44% of cases where physicians had made referrals for patients to see a counsellor or a psychologist, patients reported not being able to afford access to counselling resources. For a summary of the overall responses to survey questions regarding counselling see Table 4.

Table 4

Participants Reporting 'Yes' to Questions Assessing Willingness to Seek Counselling

Counselling $(n=190)$	f	%
1. Was referred by a physician to counselling	97	51.1
2. Believes she/he would benefit from counselling	99	52.1
3. Has seen a counsellor/psychologist before	149	78.4
4. Found seeing a counsellor/psychologist helpful $(n = 149)$	98	65.8
5. Could afford to see a psychologist/counsellor	107	56.3

Comparisons between Geographical Areas

A comparison between geographical areas on measures of interest revealed similar mean scores on variables being assessed (see Table 5). The largest differences can be seen between Canadians and the British on scores of contentment, pain, and number of concurrent conditions reported. Participants from the UK reported the lowest contentment scores (M = 3.28, SD = 1.84), while participants from Canada reported greater pain (M = 6.00, SD = 1.90) and number of concurrent health conditions (M = 3.45, SD = 2.98). Despite higher reports of pain and illness, Canadians scored their physicians higher on the PDRQ-9 (M = 27.00, SD = 10.80) than American (M = 23.60, SD = 10.60) and British participants (M = 22.06, SD = 10.59). However, differences

between mean scores were not significant (see Table 5) and larger Canadian and British samples should be sought for further comparison. Lack of significant differences suggest that, despite being from different geographical areas, all participants are members of similar group of people with FM.

Table 5.

Comparison of Mean Scores on Variables of Interest by Geographical Area

	Car	ada	U	SA	U.	UK		
	M	SD	M	SD	M	SD	F	p
PDRQ-9	27.00	10.80	23.60	10.60	22.06	10.59	0.75	.47
Illness Distress	32.64	10.52	36.47	10.52	34.94	10.12	0.77	.46
Contentment	5.09	3.45	4.44	2.47	3.28	1.84	2.27	.11
Average Pain	6.00	1.90	5.52	1.72	5.00	1.91	1.19	.31
Number of Concurrent Conditions	3.45	2.98	2.55	2.09	1.78	2.01	2.14	.12
Number of Health Care Professionals Seen	3.09	1.64	2.84	1.50	3.00	1.64	0.20	.82
Practical Problems	2.36	1.43	2.18	1.87	2.22	1.40	0.06	.95
Emotional Problems	5.36	2.46	5.32	2.46	5.67	2.25	0.17	.85
Pain Catastrophizing	21.55	10.87	24.03	12.94	22.83	12.72	0.25	.78

Comparison of geographical areas on responses to the Willingness to Seek Counselling Questionnaire appear to suggest that Canadians are the least likely to receive a referral to counselling (36%) and most likely to believe they will benefit (55%). A large portion of participants from each area reported that they had seen a psychologist or a counsellor before (Canada, 82%; USA, 78%; UK, 83%) with participants from the UK being least likely to endorse that seeing a counsellor had been helpful (53%). Finally, participants from the UK reported being the least likely to be able to afford counselling (44%) with Americans closely following (57%). Due to small numbers of Canadian and British participants, these results may not be an accurate representation of these geographical areas and larger samples should be sought before reaching conclusions on possible similarities and differences. For a full summary of comparison of

geographical differences in response to questions on the Willingness to Seek Counselling Questionnaire see Table 6.

Table 6.

Comparing Geographical Areas on Willingness to Seek Counselling

Participants reporting 'Yes' to questions assessing	Canada	USA	UK
willingness to seek counselling	(n = 11)	(n = 161)	(n = 18)
	f(%)	f (%)	f (%)
1. Was referred by a physician to counselling	4 (36.4)	82 (50.9)	11 (61.1)
2. Believes she/he would benefit from counselling	6 (54.5)	85 (52.8)	8 (44.4)
3. Has seen a counsellor/psychologist before	9 (81.8)	125 (77.6)	15 (83.3)
4. Found seeing a counsellor/psychologist helpful	7 (77.8)	83 (66.4)	8 (53.3)
5. Could afford to see a psychologist/counsellor	8 (72.7)	91 (56.5)	8 (44.4)

Analyses of Measures

PDRQ-9

To explore the dimensionality of the PDRQ-9 we used principal axis factoring with oblique rotation. The results of the scree test (see Figure 1) and eigenvalues indicated that the PDRQ-9 was a one-dimensional measure of the patient-doctor relationship ($\lambda = 7.20$, 80%). Further, reliability analysis revealed that the PDRQ-9 appeared to have good internal consistency, Cronbach's $\alpha = .97$ when used with our sample of patients with FM. Corrected itemtotal correlations ranged from r = .79 to .90, and removal of any one item did not result in a higher overall alpha coefficient.

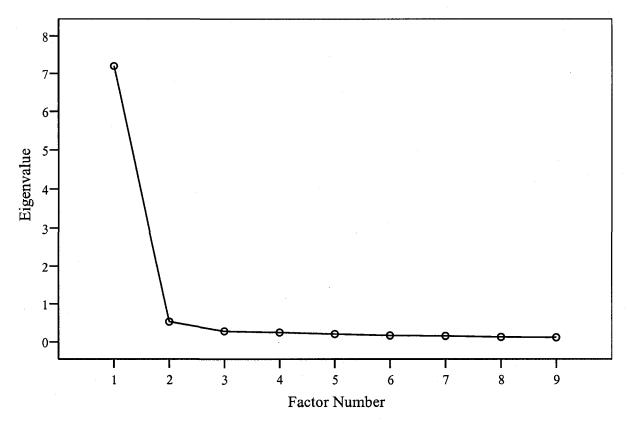


Figure 1. Scree plot for the Patient-Doctor Relationship Questionnaire-9.

Illness Distress Survey

To investigate the dimensionality of the Illness Distress Survey, again, principal axis factoring with oblique rotation was used. The results of the scree test (see Figure 2) and eigenvalues suggested that the Illness Distress Survey may contain as many as three-dimensions. Factor 1 accounting for 42% of the variance ($\lambda = 5.91$), Factor 2 accounting for 12% of the variance ($\lambda = 1.74$), and Factor 3 accounting for 9% ($\lambda = 1.23$). However, when examining item loading patterns, with criteria set at factor loadings $\geq .30$, it was observed that all items met the set criteria to be considered part of an overall construct. Further, reliability analysis revealed that the Illness Distress Survey appeared to have good internal consistency, Cronbach's $\alpha = .88$. Corrected item-total correlations ranged from r = .32 to .80, and removal of any one item did not

result in a higher overall alpha coefficient.

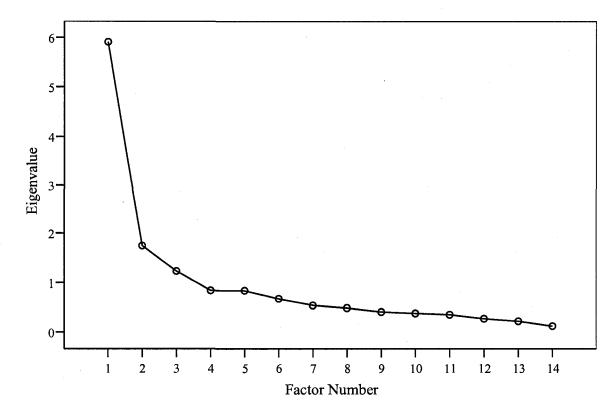


Figure 2. Scree plot for the Illness Distress Scale.

Further examination of structure and pattern matrices revealed that the Illness Distress Survey could logically be delineated in to two subscales (1) social distress due to illness, and (2) emotional distress due to illness (see Table 7). Item 14 (My quality of life during the past two weeks has been poor) loaded similarly on both factors and could be removed for the purpose of future research. Subscales were highly correlated (r = .86, p < .01) demonstrating convergent validity. The combination of a strong first factor (42% of the variance) and the very strong correlation between the two factors indicate that the Illness Distress Survey may be interpreted as being an essentially unidimensional instrument. Though the results of this analysis should be confirmed with a more diverse sample of people with FM, this survey appears to be a valid and reliable measure of illness distress containing two subscales (1) social distress, and (2) emotional distress.

Table 7.

Two Factor Structure & Pattern Matrix for the Illness Distress Survey using Principal Axis Factoring with Oblique Rotation

	Structu	re Matrix	Patter	n Matrix
	Social	Emotional	Social	Emotional
FM has interfered with my family or social life	.92	.43	.99	
FM has interfered with my daily activities	.90	.44	.96	
Pain and discomfort have cause me to limit my activities	.73	.40	.74	
FM has caused physical, emotional of financial hardship for me	.66	.41	.63	
I have had difficulty concentrating at work or at home, or on routine activities.	.64	.50	.52	
FM has interfered with my sexual life	.52	.34	.48	
FM has caused changes in my physical appearance and this concerns me	.49	.39	.40	
I have felt depressed or discouraged	.45	.88		.92
I have felt irritable or unusually angry and I have not controlled it well	.55	.77		.75
I have had difficulty coping with the stress I have experienced	.34	.70		.68
I have felt anxious or worried about my FM symptoms	.47	.66		.59
I have experienced a change in my appetite	.29	.52		.52
My sleeping habits have changed	.33	.52		.49

Emotional Problems

Using principal axis factoring with oblique rotation to assess the Emotional Problems Checklist, scree test (see Figure 3) and eigenvalues revealed that this checklist was a one-dimensional measure ($\lambda = 3.67$, 46%). Reliability analysis further indicated that the emotional problem checklist had good internal consistency, Cronbach's $\alpha = .82$. Corrected item-total correlations ranged from r = .21 to .66. Removal of item 8 (Fatigue) resulted in a negligible improvement to the overall alpha coefficient of .01. Inter-item correlations among fatigue and all other items on the Emotional Problem Checklist range from r = .10 to r = .20. Low inter-item

correlations are not surprising because 96% of the sample endorsed fatigue allowing for minimal variance. However, it is possible that fatigue is less related to emotional challenges for people with this condition and instead may be better associated with physical symptom such as pain.

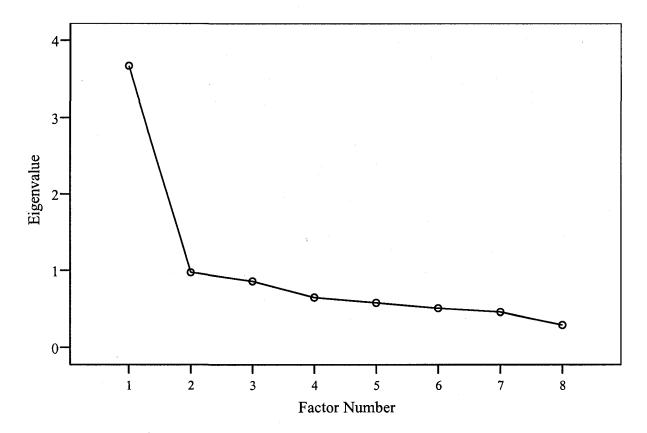


Figure 3. Scree plot for the Emotional Problems Checklist.

Practical Problems

To explore the dimensionality of the Practical Problems Checklist we used principal axis factoring with oblique rotation. The results of the scree test (see Figure 4) and eigenvalues indicated that this checklist was a two-dimensional measure of practical challenges. Factor 1 accounted for 28% of the variance ($\lambda = 2.22$), and Factor 2 accounted for 15% of the variance ($\lambda = 1.23$).

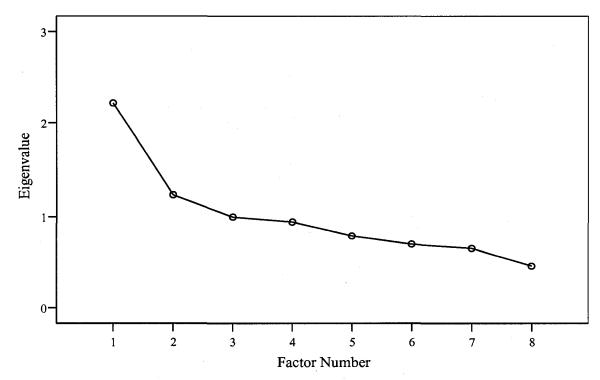


Figure 4. Scree plot for the Practical Problems Checklist.

When examining the structure matrix, with a set criterion of factor loadings $\geq .30$, it was observed that 'problems with parents' did not load adequately on the identified factors (see Table 8). Reliability analysis further revealed that the practical problems checklist appeared to have moderate internal consistency, Cronbach's $\alpha = .61$. Corrected item-total correlations ranged from r = .22 to .40, and removal of any one item did not improve the overall alpha coefficient.

Table 8.

Summary of the Structure and Pattern Matrix of the Practical Problems Checklist using Principle Axis Factoring with Oblique Rotation

Problems with	Structur	e Matrix	Pattern Matrix		
	family	general	family	general	
children	.64	.10	.72		
partner	.50	.33	.44		
childcare	.35	.25	.30		
parents	.24	.26	.16		
Housing	.13	.75		.83	
Insurance	.25	.58		.57	
Work/school	.24	.38		.34	
Transportation	.34	.35	•	.26	

Pain Catastrophizing

To explore the dimensionality of the Pain Catastrophizing Survey we used principal axis factoring with an oblique rotation. The results of the scree test (see Figure 5) and eigenvalues indicated that the Pain Catastrophizing Survey was a one-dimensional measure, $\lambda = 7.83$, 60%. Reliability analysis revealed that the Pain Catastrophizing Survey appeared to have good internal consistency, $\alpha = .94$. Corrected item-total correlations ranged from r = .44 to .83, and removal of any one item did not meaningfully improve the overall alpha coefficient.

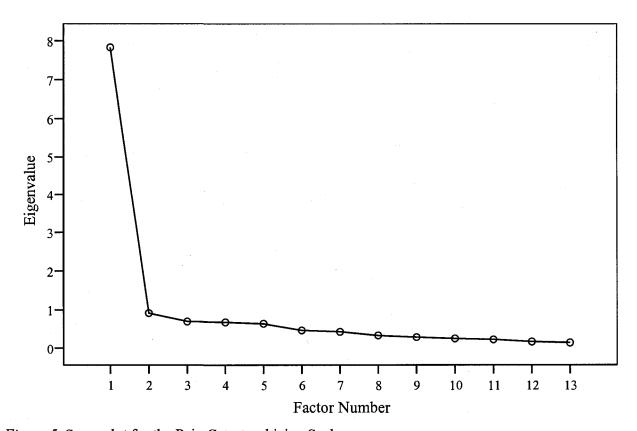


Figure 5. Scree plot for the Pain Catastrophizing Scale

Summary of Analyses of Measures

Principal axis factoring with oblique rotations was used to determine whether or not items on each survey were measuring the intended construct. In order for items to be considered part of the overall construct we set the criterion at factor loadings on the structure matrix $\geq .30$.

We further conducted reliability analyses to determine the overall internal reliability of each scale, and to explore if removal of any one item would result in a better alpha coefficient. Scree plots revealed that the PDRQ-9, the Emotional Problems Checklist, and the Pain Catastrophizing Scale were clearly one-dimensional measures of the constructs being assessed. Further reliability analyses indicated that these measures had good internal consistency, suggesting that these measures were valid and reliable measures of there intended constructs. The Illness Distress Survey was also found to be essentially unidimensional, however, also appeared to contain two highly correlated subscales. Finally, the Practical Problems Checklist indicated that it may be measuring more than one-dimension of the respective construct.

The Scree plot for the Practical Problem Checklist indicated two factors (1) problems with family and (2) general problems. Further, one item 'Problems with Parents' did not meet the set loading criterion of factor loading \geq .30. Reliability analyses revealed a moderate overall alpha coefficient (α = .61). However, removal of any one item did not improve the reliability coefficient. Some items on the Problem Checklist may not be applicable to all people with FM and this may interfere with the internal reliability of this checklist. However, all items applied to at least seven participants. Because each item could contribute to the number of problems participants had to manage along with their FM symptoms, no modifications were made to this scale. Based on the above analysis, surveys used in this research were deemed to be adequate overall measures of patients' satisfaction with their physicians, illness distress, emotional problems, practical problems, and pain catastrophizing for the purpose of this study.

Physicians' Referrals to Counselling and Patients' Ratings of their Physicians

Hypothesis 1. The first hypothesis examined the impact of counselling referrals on patients' ratings of the patient-doctor relationship. Based on previous qualitative research studies (Asbring & Narvanen, 2002; Asbring & Narvanen, 2003; Werner & Malterud, 2003), it was predicted that those who reported their physicians had suggested they receive counselling would rate their physicians lower on the PDRQ-9. A one-factor ANOVA was conducted to evaluate whether there was a difference in how patients rated their physician on the PDRQ-9 depending on whether or not the patients recalled their physicians recommending counselling. Preliminary analysis revealed that skewness (-0.56) and kurtosis (-0.78) were within acceptable ranges to meet the assumption of normality. Further Levene's test for homogeneity of variance revealed that differences in variance between groups were not significant F(1,188) = .56, p > .05. In contrast to what was predicted, mean scores on the PDRQ-9 were not significantly different for patients who recalled their physicians recommending counselling (n = 97, m = 23.71, m = 23.71,

Hypothesis 2. Research also suggests that if there is agreement between physicians' and patients' ratings, the therapeutic partnership will be enhanced (Sewitch et al., 2002). Therefore, it was predicted that patients who are referred to counselling and believe they will benefit from counselling, and those who believe they do not require counselling and are not referred, will rate the quality of their relationships with their physicians higher than those who appear to disagree with their physicians. Levene's test for homogeneity of variance revealed that differences in variance between groups were not significant F(1,188) = .36, p > .05. A one-factor ANOVA was conducted to assess for significant differences between groups. In accord with what was predicted, means on the PDRQ-9 were significantly different for patients who appeared to be in agreement with their physicians regarding whether or not they would benefit from counselling (n)

= 134, M = 24.87, SD = 10.26) versus those who appeared to not be in agreement (n = 56, M = 20.73, SD = 10.89) F(1, 188) = 6.18, p < .05). Cohen's d was 0.39, that is, a small effect size.

Predicting Openness to Counselling Referrals

Hypothesis 3. Higher scores on the Illness Distress survey, and greater numbers of reported general and emotional problems will be able to discriminate between patients who believe they will benefit from counselling from those who do not.

A discriminant analysis was conducted to determine whether three predictors (emotional problems, illness distress, practical problems) could predict whether or not participants believed they would benefit from counselling. The overall Wilk's Lamda was significant, $\Lambda = .89, \chi^2(3, N=190) = 21.16, p < .01, \text{ indicating that overall the predictors differentiate}$ between those who believe they will benefit from counselling and those who believe they will not benefit. For a summary of mean scores and confidence intervals see Table 9. The predictor variables were able to predict whether or not participants would report believing counselling would be beneficial in 67% of the 190 cases. In order to take into account chance agreement, I computed a kappa coefficient and obtained a value of .31; kappa values greater than 0 indicate a better than chance-level of prediction (Green & Salkind, 2004).

Table 9.

Means and Confidence Intervals Comparing Scores of Those Who Believe they will Benefit from Counselling to Those Who Do Not

Do you believe you would benefit from counselling?		95% Confide	F	p	
Illness distress	M	Lower bound	Upper bound		_
Yes	38.38	36.46	40.31	9.84	.002
No	33.62	31.27	35.97	9.04	.002
Emotional problems					
Yes	6.11	5.71	6.51	22.44	001
No	4.53	3.99	5.07	22.44	.001
Practical problems					
Yes	2.48	2.13	2.84	E 40	020
No	1.88	1.50	2,26	5.48	.020

Post hoc exploration. Descriptive analysis of incidents when physicians and patients appeared to agree that the patient either would or would not benefit from counselling revealed that physicians appeared to be accurate in 71% of all cases. Discriminant analysis revealed that self-reported illness distress scores, emotional problems, and practical problems accurately predicted whether or not patients believed they would benefit from counselling in 67% of cases. To further explore this, I focused on incidents where physicians and patients appeared to be in disagreement regarding whether or not patients would benefit from counselling. In 29 of these cases patients believed that they would benefit from counselling and physicians had not recommended counseling, and 27 cases were the reverse. Illness distress scores, emotional problems, and practical problems reported by patients correctly identified whether or not patients would endorse believing they would benefit from counseling in 55% of these 56 cases.

Biopsychosocial Contributions to Illness Distress and Contentment

Exploratory questions A

Based on a biopsychosocial model, biological, psychological and social factors were explored in regards to their contribution to illness distress and contentment with current life situation reported by this sample of patients with FM. Due to the method used to collect data, I was limited to the use of subjective pain reports and reported concurrent health conditions as biological factors, pain catastrophizing and emotional problems as psychological factors, and health care professionals seen in the last four months and practical problems as social factors to predict (1) illness distress and (2) contentment with one's current life situation.

Illness Distress. A standard multiple linear regression was performed between participants' ratings of illness distress as the dependent variable and number of health care professionals seen in the last four months, number of concurrent health conditions, practical problems, emotional problems, average pain level, and pain catastrophizing as independent variables. Evaluation of residuals revealed two outliers (case 120, and case 139). Case-wise

diagnostics revealed that both cases were more than 3 standard deviations away from their predicted scores. Case 120 reported a score of 11.00 on the Illness Distress survey, the predicted score was 42.07, and case 130 reported a score of 16.00, the predicted score was 37.34.

Tabachnick and Fidell (2007) argue that outliers must be removed because they affect the precision of estimation weights and impair how well results generalize to the larger population. When outliers were removed from the analyses, assumptions for normality and linearity of residuals were better met. Prior to removing outliers, observation of a histogram residual plot suggested that scores were negatively skewed.

Singularity and multicollinearity were also explored. According to Tabachnick & Fidell (2007), multicollinearity refers to when variables with the regression analysis are very highly correlated. Singularity refers to when one variable is perfectly correlated with another variable, creating redundant variables. A condition index greater than 30 for any dimension, and variance proportions greater than .50 for more than one variable, indicates problems with multicollinearity. Assumptions of a lack of singularity and multicollinearity were met for this regression analyses. The condition index reached 12.31, and no more than one variance proportion was greater than .50 for each variable. Tolerance scores less than .20 and variance inflation factors (VIF) greater than 4.00 also indicate possible problems of multicollinearity. For a summary of tolerance and VIF see Table 10.

Our final analyses revealed R for regression was significantly different from zero F(6, 181) = 43.13, p < .001, with $R_{adj}^2 = 0.58$. The R_{adj}^2 value indicates that 58% of variability in participants' illness distress ratings is predicted by number of health care professionals seen in the last four months, number of concurrent health conditions, practical problems, emotional problems, average pain level, and pain catastrophizing. Table 10 displays Pearson correlations, beta values, standardized beta values, and partial correlations. Pearson correlations (r) tell us the

strength and the direction of the relationship between each predictor variable and the dependent variable. The regression coefficients (B) reflect the increase in the predictor variables for every one unit increase in the dependent variable (slope). Beta weights (β) are similar to regression coefficients; however, in this case, data has been standardized. Standardizing the data allows us to compare the relative predictive power of the chosen predictor variables; higher absolute values indicate better predictive power. Finally, partial correlations indicate the unique contribution made by predictor variables to the variance in scores on the dependent variable after all other predictor variables have been accounted for (Garson, 1998b).

Table 10.

The Bivariate and Partial Correlations of the Predictors with Illness Distress Scores

Predictors for Illness Distress	r	В	β	Partials	Tolerance	VIF
Average pain	.41**	.94	.16	.21*	.80	1.25
Number of concurrent health conditions	.24**	.46	.09	.14	.88	1.14
Pain catastrophizing	.62**	.16	.19	.20**	.50	1.98
Emotional problems	.70**	2.01	.47	.47**	.54	1.85
Number of health care professionals seen	.10	3.79	.01	.01	.94	1.07
Practical problems	.47**	.76	.13	.17*	.75	1.33

^{*} p < .05, ** p < .01 (1-tailed)

Contentment. A standard multiple linear regression was performed between participants' ratings of contentment as the dependent variable and number of health care professionals seen in the last four months, number of concurrent health conditions, practical problems, emotional problems, average pain level, and pain catastrophizing as independent variables. Evaluation of residual plots revealed normality and linearity were within the ranges required to reliably conduct a multiple regression. Further assessment condition indexes and variance proportion revealed that singularity or multicollinearity were not problematic in this regression analysis. The condition index reached 12.25, and no more than one variance proportion was greater than .50 for each independent variable. For a summary of tolerance and VIF see Table 11.

R for regression was significantly different from zero F(6, 183) = 10.35, p < .01, $R_{adj}^2 = 0.23$. The R_{adj}^2 value indicates that 23% of variability in participants' contentment ratings is predicted by number of health care professionals seen in the last four months, number of concurrent health conditions, practical problems, emotional problems, average pain level, and pain catastrophizing. Table 11 displays the results of the regression analysis in greater detail.

Table 11

The Bivariate and Partial Correlations of the Predictors with Contentment Scores

Predictors for contentment	r	В	β	Partials	Tol	VIF
Average pain	12*	3.20	.02	.02	.80	1.25
Number of concurrent health conditions	09	-2.92	03	02	.88	1.14
Pain catastrophizing	32**	-1.55	01	01	.52	1.94
Emotional problems	49**	48	47	34**	.54	1.84
Number of health care professionals seen	15*	14	09	09	.94	1.07
Practical problems	25**	-4.45	03	03	.75	1.33

^{*} p < .05, ** p < .01 (1-tailed)

Who Helps and How do They Help

Exploratory questions B

Open-ended questions were used to investigate patients' reports of who was most helpful in managing FM symptoms, and in what ways those identified were helpful. Of the 190 participants 74 (39%) identified that physicians were most helpful in the management of their symptoms. Physicians included general practitioners (n = 33), rheumatologists (n = 19), psychiatrists (n = 10), pain specialists (n = 4), internists (n = 3), and unspecified specialists (n = 5). Most frequently participants reported that physicians were helpful in providing, monitoring, and adjusting medications for FM symptoms (n = 22). Other ways physicians were reported to be helpful included: listening, managing pain, providing support, suggesting alternative treatments,

including the patient in treatment decisions, researching FM, caring about the patient, providing referrals, and understanding the challenges of FM.

Other health care professionals identified by participants as helpful included physiotherapists (n = 7), massage therapists (n = 6), chiropractors (n = 4), naturopaths (n = 3), and acupuncturists (n = 3). Physiotherapists, massage therapists, chiropractors, and acupuncturists were reported to be beneficial in the management of pain (n = 11). Physiotherapists, chiropractors, and naturopaths were also helpful in educating patients about FM, explaining test results, and suggesting lifestyle changes including diet, and exercise. Pain clinics were identified by seven participants as most helpful. Pain clinics most often comprise a variety of health care professionals including physicians, physiotherapists, occupational therapists, and psychologists. Participants in this study reported that pain clinics helped by encouraging pain management strategies, prescribing adequate pain medications, promoting positive lifestyle changes, and providing a diagnosis. Finally, six participants reported that counsellors or psychologists were most helpful in managing their symptoms. Ways that counsellors and psychologists helped included: helping patients cope with past traumas, teaching coping strategies, identifying symptoms of depression, helping patients to feel valued, and connecting patients with community resources.

Twenty participants (11%) identified community resources as beneficial in the management of FM symptoms. Community resources included work (n = 1), church (n = 3), and FM support groups (n = 16). One participant identified that his or her workplace had been helpful by allowing for a flexible schedule. Those who reported church was helpful briefly commented on their faith in God, the support from others from their congregation, and opportunities to volunteer. Finally, FM support groups were reported to be helpful by providing people with access to others who could understand the challenges of FM, educating patients about FM, and organizing outings and other activities. An additional 14 participants reported that internet

support groups were beneficial in providing information about FM and treatments, and helping people with FM recognize they were not alone.

Forty-two participants (22%) identified interpersonal resources as most helpful including spouses (n = 22), other family members (n = 11), friends (n = 9). Interpersonal resources were reported to be beneficial in providing emotional support, helping with housework, understanding the challenges of FM, listening, and encouraging the person with FM to keep going despite symptoms. In response to who is most helpful, one woman wrote, 'my children; they kept me going in order to raise them and to continue to help them in their lives.'

Twenty-nine participants (15%) identified themselves as the most helpful person in the management of their FM symptoms. Ways participants reported helping themselves included: researching the condition and possible treatments, developing effecting coping strategies, finding support, listening to others, taking medications as needed, involving themselves in treatment decisions, advocating for themselves, and making future plans. A participant, in response to who was most helpful stated, 'Myself; because I am the only one who truly knows how I feel and what helps. I can try things that might help and rule out those that don't whilst practicing those that do.'

Most often, participants reported more than one person as helpful in the management of their FM symptoms. One-hundred-three participants (68%) identified health care professionals were most helpful in the management of FM symptoms. Seventy-five (39%) reported community and/or interpersonal resources to be beneficial, and 29 (15%) indicated they were the most helpful ones in the management of their FM symptoms. It is likely that a combination of health care professionals, community resources, family support, and individual perseverance results in the best outcomes for patients with FM. In this study four (2%) of the 190 participants reported that no one helped suggesting some may be overwhelmed by their conditions, and find it difficult to gain the support needed to manage the challenges associated with FM.

DISCUSSION

Assessment of NCCN Measures

Researchers suggest that people with FM are offended by referrals to counselling because they infer that the cause of their symptoms are being judged by physicians to be psychological rather than physical in nature (Asbring & Narvanen, 2002; Asbring & Narvanen, 2003; Werner & Malterud, 2003). Regardless of the etiology of symptoms, patients living with the challenges of FM can benefit from accessing counselling resources (Theime et al., 2006; Viane et al., 2003). Finding ways to assess openness to counselling referrals, without offending people with FM, may be helpful in enhancing patient-physician relationships and improving patient outcomes.

Three instruments used in this study were adapted from the NCCN (2005) website. These instruments include the Illness Distress Survey (see Appendix E), the Practical Problem

Checklist (see Appendix F), and the Emotional Problem Checklist (see Appendix F). The original purpose of these measures was to help patients with cancer determine if counselling would be beneficial in the management of their illness. The site advises patients with cancer that several responses to questions on the Illness Distress Survey of four or higher, on a five-point Likert type scale, indicate that support from counselling resources may be beneficial. The NCCN website further includes a problem checklist where patients can report the presence or absence of general problems, family problems, emotional problems, and symptoms.

I was interested in whether adapted versions of these surveys would prove to be effective in helping to determine when individuals with FM would be open to counselling referrals.

Questions on the Illness Distress Survey were modified by removing the word 'cancer' and replacing it with 'fibromyalgia'. Modifications I made to the NCCN's (2005) problem checklist included combining general problems and family problems under a Practical Problem Checklist, and further adding 'problems with parents' to the list. I expected that many participants in my study would be between the ages of forty and sixty years and may be caring for their elderly

parents thus contributing to the number of problems they would be managing along with their FM symptoms. Finally, the Emotional Problem Checklist was included without modifications.

The psychometric properties of these adapted surveys were also examined. The Illness Distress Survey, Practical Problems Checklist, and Emotional Problems Checklist were each assessed for unidimensionality and internal reliability. Cronbach's alpha was used to assess internal reliability, and principal axis factoring with oblique rotation, with a set criterion of factor loadings on the structure matrix $\geq .30$ to assess dimensionality. Observation of scree plots suggested that the Illness Distress Survey and the Practical Problems Checklist may have more than one dimension, and that the Emotional Problems Checklist was a unidimensional measure. The Internal reliability of the Emotional Problems Checklist was adequate ($\alpha = .82$); however, 96% of participants in this study endorsed fatigue as a problem allowing for minimal variability in response to this item. Removal of 'fatigue' from the Emotional Problems Checklist may be a consideration for future studies using this checklist in the assessment of emotional problems experienced by people with FM.

Closer examination of the Illness Distress Survey illustrated that all items met the set criteria of factor loadings $\geq .30$ in order to be considered a unidimensional scale. In addition, two subscales, one assessing emotional distress due to illness and the other measuring social distress due to illness, could be clearly identified in the pattern matrix (see Table 7). Question 14 (My quality of life during the past two weeks has been poor) loaded similarly under both subscales and could be removed for the purposes of future research. Finally, Cronbach's alpha revealed that the Illness Distress Survey had good internal reliability ($\alpha = .88$).

Observation of the Practical Problem Checklist revealed that all items did not meet the set criteria of factor loadings $\geq .30$ (see Table 8) to be considered part of a unidimensional measure. Further, two factors could be identified: general problems, and family problems. However,

'problems with parents' did not load adequately on either factor. In other words, principal axis factoring with oblique rotation separated these items back into the original form observed on the NCCN website (NCCN, 2005), with the exception that 'problems with transportation' loaded similarly on both subscales. The internal reliability of the Practical Problem Checklist was modest (α = .61) and did not improve after removal of any one item. Nearly 22% of our participants reported that having to deal with parents contributed to the number of problems they had to manage along with FM symptoms and therefore, I did not modify the scores obtained by participants on the Practical Checklist for the purposes of my analysis. However, for future research, researchers should consider using an alternative measure to assess practical problems of patients with FM. Based on the analyses I conducted, measures found on the NCCN website were deemed to be adequate measures of illness distress, emotional problems, and practical problems, for the purpose of this study. Further investigation of the validity and reliability of these measures should be carried out to confirm these findings.

Use of Health Care Resources

Patients with FM are believed to be high consumers of health care resources. In 1996, it was estimated that the annual treatment costs per patient with FM was \$2274 US dollars (Leventhal, 1999), and costs have likely increased over the past decade. In 2004, *The Journal of the American Medical Association* published a stepwise approach to the management of FM (Goldenberg et al., 2004). Step one includes confirming the diagnosis, explaining the condition to the patient, and evaluating and treating comorbid mood disorders and sleep disturbance. Step two involves prescribing low-dose tricyclic antidepressants, beginning a cardiovascular fitness program, and providing referrals to CBT. Step three entails possible referrals to rheumatologists, psychiatrists, or pain management specialists; trials of serotonin and norepinephrine reuptake inhibitors or Tramadol; and finally, if adequate relief is not achieved, combining medications or the use of anticonvulsants.

I am uncertain whether or not physicians routinely follow this approach to the management of FM. However, research suggests that people with FM are often poorly informed about their condition (Sim & Adams, 2003), struggle to have the severity of their symptoms understood by their physicians (Madden & Sim, 2006), and that physicians feel under-prepared to manage FM (Asbring & Narvanen, 2003). Moreover, physicians who become frustrated and overwhelmed by the continued complaints of patients with FM are likely to conduct unnecessary tests, and make inappropriate referrals (Asbring & Narvanen, 2003).

The results of this study indicate a small but statistically significant relationship between greater use of a variety of health care resources and decreased contentment. A possible explanation for this association is that patients who are unhappy with their current situations may look to health care resources to resolve their discontent. Additionally, decreased contentment may be associated with greater use of health care resources because patients wait weeks to months for their medical appointments. They may put their regular activities on hold waiting for symptoms to abate, and can be disappointed by treatments that do not result in symptom resolution.

In the case of FM, specialists will rule out conditions likely already ruled out by general physicians. Treatments offered by specialists are the same or similar to treatments offered by general physicians and do not eliminate FM symptoms. Additionally, use of other health care resources including physiotherapy, counselling, and massage therapy are intended to be helpful in the management of FM. People with FM seeking a cure may be disappointed by treatment approaches that require their active participation and do not result in symptom resolution. Excessive use of health care resources may be an indicator of poor adjustment to illness, or lack of accurate information regarding FM.

The results of this study suggest that the majority of people with FM, who took part in this study, access three or more different types of health care resources within a four month

period. The most frequently sought out professionals include general practitioners (80%), and specialists (64%); with counsellors being a distant third (24%), and massage therapists following closely behind (22%). Eighty-five percent of participants in this study had at least one additional concurrent health condition. This may explain the high use of specialized care for patients whose FM symptoms may have otherwise been adequately addressed by general practitioners.

Goldenberg et al. (2004) report rheumatologists provide care for less than 20% of patients with FM. Other specialists accessed by participants in this study for the management of FM symptoms included psychiatrists, pain specialists, and internists.

When asked who was most helpful in the management of their FM symptoms, 58% of participants identified health care resources. Seventeen percent of participants identified general practitioners as most helpful in the management of their FM symptoms, and 22% of participants reported specialists were most helpful. Participants reported physicians helped in the management of FM by providing, monitoring, and adjusting medications for FM symptoms. Physicians further assisted patients by including them in treatment decisions, providing support, and understanding the challenges of FM. Finally, some participants reported that their physicians assisted them by researching FM, suggesting alternative treatments, and providing referrals.

Other health care professionals identified by participants as helpful included physiotherapists, massage therapists, chiropractors, naturopaths, and acupuncturists. Participants reported that these health care professionals were beneficial in the management of pain, in increasing their understanding of FM, explaining test results, and suggesting lifestyle changes including diet and exercise. Participants also reported that counsellors or psychologists were helpful in managing their symptoms. Ways counsellors and psychologists helped included teaching coping strategies, identifying symptoms of depression, helping the patient feel valued, and connecting patients with community resources. Finally, participants reported that multimodal treatment programs offered by pain clinics had been beneficial by encouraging pain management

strategies, prescribing adequate pain medications, promoting positive lifestyle changes, and providing a diagnosis.

In line with participants' responses regarding how health care professionals help, Haugli et al. (2004) have found that people with chronic, diffuse symptoms desire a diagnosis. Having a diagnosis validates patients' experiences of symptoms. Not having a diagnosis results in patients feeling disbelieved and can exacerbate the distress experienced by patients. Further, people with FM reported benefiting from being educated about their condition and being involved in treatment decisions. Knowledge of FM and possible treatments are required so that patients can engage in effective illness self-management strategies (Bieber et al., 2006). Patient education and involvement in treatment decisions also may enhance patients' abilities to cope with symptoms, and improve adherence to prescribed treatments and self-management strategies (Bieber et al., 2006).

Finally, participants reported that health care professionals helped by providing empathy and support. Daltroy (1993) reported that the physician has three major communication goals: (1) eliciting the patient's problem and history, (2) negotiating a treatment regime that is acceptable to the patient, and (3) educating the patient about the illness and treatment. Conveying empathy and reinforcing the patient's ability to mange the condition were deemed to be secondary.

Paradoxically, without first establishing an empathetic and support environment the primary goals may not be achieved. If patients do not perceive their physicians to be empathetic and supportive, they are less likely to be forthcoming with personal information, they may fear openly disagreeing with their physicians, and further are less likely to adhere to treatment plans (Halpern, 2006).

Traditionally, physicians were expected to take a detached and objective approach to patient care (Halpern, 2006). However, researchers have found that emotionally engaged physicians generate more trust, decrease anxiety, and improve patients' abilities to cope with

illness (Haugli et al., 2004). Physicians are now encouraged to be aware of their own feelings regarding patients and to differentiate between sympathy and empathy. Sympathy by Halpern's (2006) definition is resonating with another's general mood, while empathy involves emotional attunement and interest in another's perspective. Health care professionals who show an interest in patients' perspectives and who are more self-aware are less likely to ignore, pathologize, or transfer challenging patients. They are also more likely to identify signs of emotional distress, to provide adequate treatment, and to refer patients to appropriate health care resources.

Physicians' Referrals to Counselling and Patients' Ratings of their Physicians

CBT is part of a multidisciplinary approach recommended, along with tricyclic

antidepressants and cardiovascular exercise, for the treatment of FM (Goldenberg et al., 2004).

CBT is the most well researched counselling approach to the management of FM (Bradley et al., 2003; Nielson & Jensen, 2004; Theime et al., 2006). However, other approaches including ACT (Viane et al., 2003) and Operant Behavioural Therapy (Theime et al., 2006) have also demonstrated favorable outcomes for patients with chronic pain conditions. Potential benefits of these behavioural approaches include improved physical functioning, pain reduction, and decreased emotional distress (Theime et al., 2006; Viane et al., 2003). Despite research results indicating positive outcomes for patients with FM through the use of CBT, physicians may be hesitant to refer patients to counselling resources.

The results of previous studies suggest that people with FM are offended by referrals to counselling and that referrals may be damaging to the patient-physician relationship (Asbring & Narvanen, 2002; Asbring & Narvanen, 2003; Werner & Malterud, 2003). Patients may believe that referrals to counselling indicate that their physicians doubt that physical problems exist (Asbring & Narvanen, 2003; Werner & Malterud, 2003). Further, diagnoses of emotional problems are associated with greater stigma than physical challenges (Werner & Malterud, 2003). Therefore, people with FM are likely to reject counselling referrals (Asbring & Narvanen,

2003; Werner & Malterud, 2003) and such referrals may negatively impact on how patients rate their relationship with their physicians.

The findings of this study suggest that physician referrals to counselling alone do not negatively influence patients' satisfaction with their physicians. In fact, 52% of the participants in this study believed they would benefit from counselling. Instead, it appears that physician-patient agreement regarding the benefit of counselling is influential in patients' ratings of their physicians. Patients who report that their physicians are in agreement regarding whether or not they will benefit from counselling rate their satisfaction with their physicians higher. These findings are in line with research on physician-patient discord which suggests that patients are more satisfied with their physicians when there appears to be a close agreement between physicians and patients regarding physical limitations, emotional distress, and treatment recommendations (Sewitch et al., 2002). Higher scores on the PDRQ-9 may not simply be a reflection of physicians accurately assessing whether or not patients are open to counselling referrals. Instead, it seems plausible that physicians who have developed therapeutic relationships with their patients are better able to direct treatment in a manner consistent with patients' individual preferences.

Predicting Openness to Counselling Referrals

Daltroy (1993) reports that physicians may be reluctant to elicit emotional concerns due to time constraints and feeling unprepared to manage psychosocial issues. Moreover, patients may give clues to underlying psychosocial problems but are unlikely to openly share these concerns unless asked directly (Daltroy, 1993; Halpern, 2006). Failure to acknowledge psychosocial issues limits patients' satisfaction with their care and may result in more frequent and unproductive appointments (Halpern, 2006). Assessment of illness related distress, emotional problems, and practical problems may help physicians decide who is likely to benefit and be open to counselling referrals. Conversely, making referrals to counselling that are perceived by

the patient to be unnecessary may negatively impact on the patient-physician relationship.

Therefore, being able to predict whether or not patients will be open to counselling referrals may help in the development and maintenance of therapeutic relationships.

In this study, the majority of physicians and patients appeared to be in agreement regarding whether or not the patient would benefit from counselling (71%). It is unknown how physicians, in these cases, decided whether or not to make referrals to counselling resources. Goldenberg et al. (2004) suggest that referrals to counselling be made after the diagnosis of FM has been confirmed, the patient has been educated about his or her illness, and an evaluation of comorbid mood disorders and sleep disturbance has been completed. Banez and Gallagher (2006) recommend that physicians refer people with chronic pain problems to psychological care when symptoms are first presented. They suggest counselling resources be offered as an opportunity to learn the influence of stress and emotions on symptoms, and to become skilled at new ways in which one can cope with pain in order to return to regular activities.

I used Illness Distress scores, number of reported emotional problems, and number of reported practical problems to differentiate between patients who would be open to counselling from those who would not. Higher scores on all three scales discriminated between those who believed they would benefit from those who would not in 67% of cases. Further analyses revealed that in 55% of the cases where physicians and patients disagreed, scores on the aforementioned scales accurately predicted whether or not patients would endorse believing they would benefit from accessing counselling resources. In cases where physicians are uncertain whether or not to refer patients to counselling, having patients complete these surveys could help physicians differentiate between those who would be open to counselling referrals from those who would not.

Biopsychosocial Contributions to Illness Distress and Contentment

Weiner (2007) reports that from a biomedical perspective disease is an organ specific, pathophysiological state that reduces organ function below what is expected for the patient's age and sex. When pathology cannot be objectively observed, disease does not exist and patients may be criticized for engaging in illness behaviours. The success of the biomedical model reinforces the importance of addressing underlying pathology. In the case of chronic pain, underlying pathology may include degeneration, inflammation, and joint instability. Negative test results, continued complaints, and poor treatment compliance suggest the need to further consider psychosocial issues in the maintenance of chronic pain and disability. From a biopsychosocial perspective, the primary determinants of patients' complaints are psychosocial factors that include illness beliefs, coping strategies, fears, and emotional challenges.

Before diagnosing a patient with FM it is important that underlying conditions that can be successfully treated by biomedical interventions are ruled out. Fitzcharles and Esdaile (1997) advise physicians to explore all other possible diagnoses before attributing musculoskeletal pain to FM. This includes conducting a family history that explores the presence of painful conditions in first-degree relatives. Further, continued monitoring is recommended because many rheumatological conditions are only diagnosable after several years of symptoms. Health care professionals examining and treating chronic pain from a biopsychosocial perspective would carry out a thorough clinical examination; be wary of thoughts and experiences that may be influencing pain perception and behaviours; and address individual stressors, psychosocial challenges, and health behaviours (Bergman, 2007).

Rather than exploring biopsychosocial factors as possible cause for FM, I take the position that FM is a chronic condition that must be managed, and the influence of biopsychosocial factors on illness distress and contentment is investigated. In this study, 'subjective pain reports' and 'reported concurrent health conditions' were deemed to be

biological factors, 'pain catastrophizing' and 'emotional problems' were examined as psychological factors, and 'health care professionals seen in the last four months' and 'practical problems' were identified as social factors that may influence illness distress and contentment.

Illness distress, for the purposes of this study, is defined as challenges one experiences in relation to FM symptoms. The Illness Distress Survey looks at self-reports of the impact of FM on social and emotional well-being. High scores on this scale may indicate poor adjustment to illness. Contentment, conversely, can be defined as a feeling of peace with one's self, and current life situation (Fredrickson, 1998), and may be a reflection of successful adjustment to FM symptoms. After accounting for all other variables, patients' reports on the emotional problem checklist were the greatest predictor of illness distress and contentment. This suggests that addressing emotional challenges may help people better manage the challenges of FM. High reports of emotional problems, and their association with greater levels of illness distress and lower levels of contentment, further corroborate the potential benefit of counselling resources for people diagnosed with FM. Though counselling may not be effective in eliminating FM, it is likely to decrease emotional difficulties and to improve management of FM symptoms. Sixtyeight percent of participants in this study, who had accessed counselling, reported that it had been helpful.

Other than Health Care Professionals: Who Helps and How

Multidisciplinary approaches in the treatment of FM can improve patient outcomes. However, symptoms completely resolve in just 3% of cases, and only 50% of patients report adequate symptom relief (Leventhal, 1999). Acknowledging the limitations of current medical treatments and encouraging patients to continue living valued lives despite symptoms may be pivotal in helping patients adjust to FM (McCracken et al., 2005). Helping patients to identify resources in the community, and to educate their employers and families regarding the nature of

FM, may help patients obtain the support required to effectively manage symptoms and daily challenges with less reliance on health care resources (Madden & Sim, 2006).

Nearly 11% of participants identified community resources as most beneficial in the management of FM symptoms. Community resources included work, church, and FM support groups. One participant identified that his or her workplace had been helpful by allowing for a flexible schedule. Research on employment and chronic pain suggests that employers may offer employees with chronic pain problems flexible work schedules, job sharing, or other alternative arrangements (Byrne & Hochwarter, 2006). Further, a belief that employers recognize the contributions made by their employees, and that they care about their well-being, seems to translate into increased effort to maintain job performance despite chronic pain (Byrne & Hochwarter, 2006).

The benefits of perceived support seem to permeate all domains of life. Participants reported benefiting from the support provided by members of their congregations, and FM support groups in their communities and online. Participants reported that FM support groups helped by creating access to others who could understand the challenges of FM, providing information, and organizing activities. Beyond providing support, belonging to a church offered people limited by FM opportunities to volunteer.

Twenty-two percent of participants identified interpersonal support as most helpful. Persons providing interpersonal support included family members, and friends. Family and friends helped people with FM by providing emotional support, helping with housework, understanding the challenges of FM, listening, and encouraging the person to keep going despite symptoms. Fifteen percent of participants identified themselves as the most helpful person in the management of their FM symptoms. Ways participants reported helping themselves included: researching the condition and possible treatments, developing effecting coping strategies, listening to others, taking medications as needed, involving themselves in treatment decisions,

advocating for themselves, making future plans, and finding support. Currently, there is not a cure for FM and treatments offered by health care professionals are limited in effectiveness (Asbring & Narvanen, 2003). Patients living with this disorder often have equal or greater knowledge of their condition in comparison to health care professionals (Asbring & Narvanen, 2003). It seems plausible that the best patient outcomes are due to efforts made by patients to manage their symptoms and support provided by others, rather than due to medical interventions (Asbring & Narvanen, 2003).

Conclusions

Participants broadly reported seven ways that health care resources can be helpful in the management of FM: (1) by providing a diagnosis; (2) by educating the patient about the meaning of test results, their illness, and treatment options; (3) by including the patient in treatment decisions, and monitoring the effects of treatment; (4) by promoting health behaviours; (5) by helping people with FM to develop effective coping strategies; (6) by informing them of community resources; and finally, (7) by providing empathy and support. The patient-physician relationship can be influential in how patients define and manage their illness. Empathetic and supportive relationships encourage open communication, and are helpful in eliciting patients' underlying concerns and desired approaches to treatment (Halpern, 2006). Though patients can benefit from medical treatments (Turk, 2004), FM symptoms are unlikely to disappear (Halpern, 2006). Therefore, general practitioners may want to consider the potential benefits of community support, interpersonal support, and illness self-management in optimal patient outcomes.

Participants in this study identified work, church, and FM support groups as community resources that were helpful in the management of their symptoms. Participants reported that employers can help people with FM by providing flexible work schedules, while church and FM support groups can help by providing supportive networks, planning group activities, and creating opportunities to volunteer. Community and internet support groups further provide

information about FM, and create opportunities for people with FM to connect with others who have similar challenges.

Interpersonal resources identified as beneficial included spouses, other family members, and friends. Participants reported that interpersonal resources can help by providing emotional support, helping with housework, understanding the challenges of FM, listening, and encouraging the person with FM to keep going despite symptoms. Finally, participants shared that they helped themselves by researching the condition and possible treatments, developing effective coping strategies, finding support, listening to others, taking medications as needed, involving themselves in treatment decisions, advocating for themselves, and making future plans.

Based on literature that states that less than 50% of people with FM will be satisfied with the outcome of medical interventions (Goldenberg et al., 2004), it seems important that health care professionals acknowledge their limitations and take a broader perspective in the management of FM that includes community, family, friends, and intrapersonal resources. Further validating patients' experiences of symptoms, and identifying their individual strengths, and potential resources may empower patients to manage their illness with less reliance on health care resources (Haugli et al., 2004). Researchers suggest that patients with chronic pain who cope poorly with chronic pain have difficulty establishing supportive relationships (Savelkoul et al., 2000). Patients indicating that they lack social support may also report greater emotional distress and physical limitations (Gamsa, 1990), and would likely benefit from referrals to counselling resources.

Results from my study suggest that emotional problems contribute significantly to illness distress and decreased contentment even after accounting for pain, concurrent health conditions, pain catastrophizing, number of health care professionals seen, and practical problems.

Addressing emotional challenges may help people with FM better manage their condition.

However, to benefit from referrals to counselling resources it is necessary that patients agree that

accessing counselling resources will be beneficial. Results of this study indicated that in 71% of cases physicians and patients agreed upon whether or not referrals to counselling would be beneficial, and 52% of participants believed they would benefit from seeing a counsellor. The 28% of participants who disagreed with their physicians regarding whether or not they would benefit from counselling rated the quality of their patient-physician relationship significantly lower than those who agreed. This suggests that a better therapeutic relationship may guide physicians in making treatment recommendations that are in line with patients' understandings of illness, and desired treatment approaches.

I used self-reports of emotional problems, practical problems, and illness distress scores to try to differentiate between participants who would benefit from counselling from those who would not. In 67% of cases, higher scores on these measures were able to correctly classify participants as either open or not open to counselling referrals. The physicians of the participants in this study appear to have been better able to differentiate who would, or would not, be open to counselling referrals than the measures used. Moreover, those who were in agreement with their patients received higher PDRQ-9 scores than those who were not. Based on these results, it appears that surveys that assess for psychosocial factors may be beneficial in facilitating discussion about possible treatment options, but should not displace the time needed to establish a therapeutic relationship with people who have FM.

Questions on the Illness Distress Survey and the Emotional and Practical Problems

Checklist are easy to interpret and may be sensitive to participants attempting to generate desired conclusions. Though this sensitivity can be problematic in research, it may be beneficial in general practice. Patients who are overwhelmed by their symptoms may report highly on these scales to elicit greater support from their attending physicians and to possibly access other health care resources. Acknowledgement and discussion regarding the challenges patients experience

due to FM may reduce symptom complaints and enhance the therapeutic relationship (MacDonald, 2004; Werner & Malterud, 2003).

Conversely, patients who are concerned that endorsing emotional difficulties will imply that their symptoms exist in relation to psychological rather than somatic problems may endorse minimal or no emotional challenges. This would indicate that these patients would not likely benefit from counselling referrals, and may be offended by such referrals. Low levels of psychosocial difficulties reported on these questionnaires create opportunities for physicians to question how patients manage the fatigue and pain associated with FM. Acknowledging and complimenting patients' efforts to manage their symptoms could reinforce self-management strategies (Werner et al., 2003). Furthermore, discussing the illness from a biopsychosocial perspective could broaden patients' understanding of their illness and may help patients form more holistic views of health. Patients who perceive that their health care professionals acknowledge their emotional distress may be the result of struggling with difficult symptoms, rather than the cause of FM, may be more willing to disclose emotional challenges, and to employ recommended treatments that include tricyclic antidepressants, and CBT (Goldenberg et al., 2004).

Limitations

I collected data for this study using a convenience sample of community support groups listed on the internet and a contact list of participants who had contacted me after taking part in a previous online study. Contact with all potential participants was limited to brief e-mails that introduced the study, responded to participants' questions, informed me they had let others know about the study, or provided results of previous research. Due to collecting data on the internet, without requesting identifying information, it is impossible for me to determine who chose to take part. Results might not be representative of all patients with FM. The majority of

participants in this study were middle-aged, Caucasian females, which are typical characteristics of participants in FM studies (Asbring & Narvanen, 2003).

Due to poor representation, results may not generalize to males or minority populations with FM. FM is four to five times more likely to be diagnosed in women than men. The ratio of women to men in this study was nearly 32:1. This may reflect that women with FM are more likely to take part in support groups than men with FM. Moreover, members of support groups, and those with internet access, may also be better educated about their condition and treatment options than those who do not (Ziebland, 2004). Participants who are better educated may be more open to counselling resources than those who lack knowledge of the potential benefits.

The high levels of agreement between physicians and patients regarding the potential benefit of counselling resources may be specific to FM support group members. Members of support groups are likely to inform each other of supportive health care professionals who acknowledge FM as a legitimate illness. People with FM who do not have access to support groups may have greater difficulties finding empathetic health care professionals and, therefore, lower frequencies of agreement and decreased PDRQ-9 scores may be found among a more diverse sample.

Further limitations of conducting research over the internet include the lost opportunity to take objective measures, observe the respondents' tone and body language when responding to open ended questions, and the inability to contact anonymous respondents to confirm the accuracy of my interpretations (Robinson, 2001). Advantages of conducting research over the internet included access to participants across the Canada, the USA, and the UK. Additionally, participants could take part from their homes and might have felt more comfortable sharing information knowing they could not be identified (Robinson, 2001). A similar study should be conducted that randomly selects participants, beyond those who take part in support groups, to discover whether these findings can be generalized to the larger population of people with FM.

Future Research

Current research focuses on problematic coping behaviours, and social and individual characteristics that contribute to pain behaviours and patient outcomes (Clark-Callister, 2003; Edwards et al. 2004; Gamsa, 1990; Gaston-Johnsson et al. 1990). Research looking at how people with FM adjust and learn to manage the challenges of their condition is needed so that health care professionals can encourage behaviours that minimize symptoms, and motivate patients to live active lives despite symptoms. Further, expanding on research that explores how different health care professionals approach patients with FM could also be beneficial in directing patient care. Research has been done examining how physicians, occupational therapists and physiotherapists, define and treat the problems associated with FM (Asbring & Narvanen, 2003; Sim & Adams, 2003). However, patients with FM report benefiting from a larger variety of health care professionals such as chiropractors, acupuncturists, counsellors, and naturopaths. Understanding how these professionals approach FM may help in guiding physicians and patients in the development of individualized multidisciplinary treatment plans that will help patients in achieving their desired health outcomes.

Moreover, an institutional ethnography that directly observes how physicians interact with patients who have FM may give further insight into the challenges experienced by patients and physicians. Research guided by institutional ethnography could consider all stakeholders in the process of developing guidelines that facilitate better therapeutic relationships between physicians and patients with this condition. Information gained from this study could be helpful in providing physicians and patients with the necessary communication skills to enhance patients' outcomes and decrease physician burnout.

Finally, this study included participants from Canada, the USA, and the UK.

Comparisons between geographical areas suggest there may be differences between counselling referral practices and patient satisfaction with care. Low numbers of participants from Canada

and the UK, in this study, make it impossible to draw meaningful conclusions regarding geographical differences. Disparity between Canadian, American, and British approaches to treatment and patient satisfaction with care may provide insight into the influence various health care systems have on patient outcomes.

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APPENDIX A

Ethics Approval

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Natasha Egeli

CC: Peter MacMillan

From: Henry Harder, Chair

Research Ethics Board

Date: February 2, 2006

Re: E2006.0101.002

The physician's role in facilitating adjustment to Fibromylagia

Thank you for submitting the above-noted research proposal and requested amendments to the Research Ethics Board. Your proposal has been approved.

Good luck with your research.

Sincerely,

Henry Harder

APPENDIX B

Initial Contact E-mail

Consent Form

Debriefing Form

Initial Contact E-mail

Hi		

I'm a graduate student from the University of Northern British Columbia. I am doing a project on the physician role in helping patients adjust to chronic pain. I'm e-mailing you because you have taken part in my research before, or because I found you listed on the internet as someone who supports people with fibromyalgia. If you have physician diagnosed fibromyalgia and are over the age of 18, I hope you will take part in my project. To take part, you simply have to click on the link below. It will take you to a site where additional information about the study will be provided. After reading that information, you can begin the survey. It will take approximately 25 minutes to complete. If you have any questions or concerns, you can e-mail me at egeli@unbc.ca. You do not have to provide any identifying information to take part in this study. By completing the survey you are consenting to take part in this research project.

If you know anyone else who may be interested in taking part, please forward this e-mail or have them contact me at egeli@unbc.ca

(Please scan you computer for viruses before mass e-mailing this message to support group members)

Link to the research survey:

http://survey.unbc.ca/public/survey.php?name=FM_research99

Thank you for your support!

Sincerely, Natasha Egeli

University of Northern British Columbia Informed Consent

The Physician's Role in Facilitating Patient Adjustment to Fibromyalgia

Graduate Project

Principle Investigator: Natasha Egeli egeli@unbc.ca

Supervisor: Dr. Peter MacMillan 250-960-5828

Co-supervisor: Dr. Ken Prkachin 250-960-6633

Purpose

This study surveys patients with fibromyalgia to assess the extent to which the doctor-patient

relationship accounts for patient adjustment to chronic pain.

Potential Risks

This study requires you to complete an online survey. There is minimal risk involved in taking

part in this study. However, some questions may stir-up negative emotions including feelings of

sadness, anger and/or frustration. If you find questions too distressing you may exit the survey at

anytime. If you require further support you can consult with your physician or local crisis line

regarding support available in your community.

Potential Benefits

Research that examines doctor-patient relationships and patient outcomes has the potential to

improve future care for patients with fibromyalgia.

You were chosen to take part in this study because you have physician diagnosed fibromyalgia

and are over the age of 18. To take part in this study, you must fully read this consent form

before proceeding to complete the survey questions. The survey contains questions that inquire

about demographic information, doctor-patient relationships, the impact of fibromyalgia, pain

acceptance, and worry about pain. It will take approximately 25 minutes to complete.

Researchers (Natasha Egeli and Dr. Peter MacMillan) will have access to your survey responses.

Participation in this study is voluntary and you can withdraw at anytime without penalty. There

are no rewards being offered for participation in this study.

Confidentiality & Anonymity

We will not be collecting any identifying information within the survey. Survey data will be downloaded into an Excel file and will not be destroyed. By completing the survey you are consenting to participate in our project.

Results of this study may be presented at a conference and/or submitted for publication in a peer reviewed journal. If you would like a summary of the results of the study please e-mail Natasha Egeli at egeli@unbc.ca and a copy will be e-mailed to you when the study is complete.

Consent

By completing the survey you are consenting to take part in this study.

If you have any questions or inquiries you can contact Natasha Egeli at egeli@unbc.ca or Dr. Peter MacMillan at 250-960-5828.

Complaints may be addressed to the Office of Research, UNBC, 960-5820, or reb@unbc.ca.

University of Northern British Columbia Debriefing Form

The Physician's Role in Facilitating Patient Adjustment to Fibromyalgia

Graduate Project

Principle Investigator: Natasha Egeli egeli@unbc.ca

Supervisor: Dr. Peter MacMillan 250-960-5828

Co-supervisor: Dr. Ken Prkachin 250-960-6633

The purpose of this study was to assess the physician's role in facilitating the patient's adjustment to chronic pain. A better understanding of the physician's role in facilitating patient adjustment to chronic pain may be important when creating best practice guidelines. Physicians who understand their role in the creation of maladaptive patient behaviours may respond with appropriate empathy and more effective communication skills. This may result in better patient outcomes and decreased help seeking behaviours.

Using this data, we also hope to assess patients' need for emotional support and the willingness of patients to seek counselling.

For more information we recommend the following resources:

Living a Healthy Life with Chronic Conditions

by Halsted Holman, David Sobel, Diana Laurent, Virginia Gonzalez, Marian Minor, Kate Lorig.

The Arthritis Foundation's Guide to Good Living with Fibromyalgia by Arthritis Foundation

Thanks again, for participating in this project.

Sincerely,

Natasha Egeli

Complaints may be addressed to the Office of Research, UNBC, 960-5820, or reb@unbc.ca

APPENDIX C

Demographic Information

1. Demographic Information (please print clearly)

Country:		Gender	:									
Year of Birth:	Marital Status:											
Years with FM symptoms:	symptoms: Years with FM diagnosis:											
Ethnicity/Race:	ce: Occupation:											
Estimated Yearly Income:	_0 – 9 999	10 0	00 -	19	999)		2	0.0	000	– 2 9	999
·	_30 000 – 39	999 _	4	0 00	0 –	49	99	9		5	50 00	00 – more
Highest Educational level comp	oleted: Compl	eted Gra	de _									
Grade 12	_ Some Colleg	ge/trade s	cho	ol			_ D	iplo	om	a		
BA/BSc	Masters							Ph	D			
Do you have other chronic heal	th conditions?	Yes 1	No									
If yes what condition do you ha	ve?										· · · · · ·	
What is your pain level today?		no pai			3	4	5	6			9 rem	10 e pain
What has your pain level been during the past month?	on average	no pa		2	3	4	5	6	7			10 ne pain
How content are you with your situation?	current life	not at		2	3	4	5	6	7		9 comp	10 pletely
Please place a check mark besi months .	de each health	care res	ourc	e yo	u h	ave	ac	ces	sec	l in	the	past 4
Doctor (GP)	[] Doctor	(Special	st)			[] I	Phy	sio	the	rapis	st
[] Occupational therapist	[] Massag	e therapi	st			[](Chi	rop	rac	tor	
[] Psychologist/counsellor	[] Acupun	cturist				[] §	Soc	ial	Wo	rker	
[] Pain Clinic	[] Dietitia	n				[] [Vat	urc	pat	h	

APPENDIX D

Patient-Doctor Relationship Questionnaire-9

Patient-doctor relationship questionnaire-9

You will read nine statements that a person can make about his or her primary care physician. Please choose the appropriateness of each statement for your primary care physician by marking one number per statement. The meanings of the numbers are as follows.

- 1 = not at all appropriate
- 2 = somewhat appropriate
- 3 = appropriate
- 4 = mostly appropriate
- 5 = totally appropriate

1	My physician helps me	1	2	3	4	5
2	My physician has enough time for me	1	2	3	4	5
3	I trust my physician	1	2	3	4	5
4	My physician understands me	1	2	3	4	5
5	My physician is dedicated to helping me	1	2	3	4	5
6	My physician and I agree on the nature of my health care condition	1	2	3	4	5
7	I can talk to my physician	1	2	3	4	5
8	I feel content with my physician's treatment	1	2	3	4	5
9	I find my physician easily accessible	1	2	3	4	5

APPENDIX E

Illness Distress Survey

The	self-assessment	auestionn	aire for	nationts
1 ne	seu-assessmem	uuesuonn	iuire ivi	· vanems

The self-assessment questionnaire for patients
Every patient experiences some of these symptoms. Please circle a number that you feel best reflects how you have been feeling during the past two weeks.

1. I have felt	t anxious or v	vorrie	ed abou	ıt my f	ibromy	⁄algia	symptoms
	Not at all	1	2	3	4	5	All the time
2. I have felt	t depressed o	r disc	ourage	ed			
	Not at all	1	2	3	4	5	All the time
3. I have felt	t irritable or ι	unusu	ally an	igry an	d I hav	e not	controlled it well
	Not at all	1	2	3	4	5	All the time
My sleepi	ing habits hav	ve cha	inged				
•	Not at all	1	2	3	4	5	All the time
5. I have exp	perienced a c	hange	in my	appet	ite		
	Not at all	1	2	3	4	5	All the time
6. I have had	d difficulty co	oncen	trating	at wo	rk or at	hom	e, or on routine activities.
	Not at all	1	2	3	4	5	All the time
7. Fibromya	lgia has inte	rferec	l with	my dai	ly activ	vities	
	Not at all	1	2	3	4	5	All the time
8. Fibromya	lgia has inter	fered	with n	ny fam	ily or s	ocial	life
	Not at all	1	2	3	4	5	All the time
9. Fibromya	lgia has inter	fered	with n	ny sexi	ual life		
	Not at all	1	2	3	4	5	All the time
10. Pain and	l discomfort l	have o	cause n	ne to li	imit my	/ activ	vities
	1100 40 411	1	2	3	4	5	All the time
11. Fibromy	algia has cau	ised p	hysica	l, emo	tional c	of fina	ncial hardship for me
	Not at all	1	2	3	4	5	All the time
12. Fibromy	algia has cau	ised c	hanges	s in my	physic	cal ap	pearance and this concerns me
	Not at all	1	2	3	4	5	All the time
13. I have ha	ad difficulty	copin	g with	the str	ess I ha	ave ex	rperienced
	Not at all	1	2	3	4	5	All the time
14. My qual	ity of life du	ring tl	ne past	two w	eeks h	as bee	en:
	Excellent	1	2	3	4	5	Poor

APPENDIX F

Problem Checklists

Problem Checklists

Please indicate if any of the following have been causes of distress in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Emotional Problems
		Housing			Worry
		Insurance			Fears
		Work/School			Sadness
		Transportation			Depression
		Child care			Nervousness
Ċ		Dealing with children			Loss of interest in usual activities
		Dealing with partner			Anger
		Dealing with parents			Fatigue

APPENDIX G

Willingness to Seek Counselling

Willingness to Seek Counselling

	Yes	No	Not Applicable
Has your doctor ever suggested that you might benefit from seeing a psychologist or a counsellor?			
Do you think you would benefit from seeing a counselor/psychologist?			
Have you ever seen a psychologist/counsellor to help you with your fibromyalgia?			
Was seeing a psychologist/counsellor helpful?			
Could you afford to see a psychologist or a counsellor if you wanted to?			

Willingness to Seek Counselling

	Yes	No	Not Applicable
Has your doctor ever suggested that you might benefit from seeing a psychologist or a counsellor?			
Do you think you would benefit from seeing a counselor/psychologist?			
Have you ever seen a psychologist/counsellor to help you with your fibromyalgia?			
Was seeing a psychologist/counsellor helpful?			
Could you afford to see a psychologist or a counsellor if you wanted to?			

APPENDIX H

Pain Catastrophizing Scale

Pain Catastrophizing Scale
Place a tick mark in the box that best describes the intensity you experience the following thoughts and feelings when you are in pain. (Tick one box for each statement)

		Not at all	mildly	moderately	severely	extremely
1	I worry all the time whether the pain will end					
2	I feel I can't go on					
3	it is terrible and I think it is never going to go away.					
4	I feel it is awful and it takes over my life.					
5	I can't stand being in pain anymore					
6	I am afraid the pain is going to get worse					
7	I keep thinking of other painful events					
8	I want pain to go away					
9	I can't keep it out of my mind					
10	I keep thinking about how much it hurts					
11	I keep thinking about how much I want the pain to stop					
12	there is nothing I can do to reduce the pain					
13	I wonder if something serious might happen					