

A WIFE OR A PATIENT: FIBROMYALGIA PATIENTS' COMMUNICATION
BEHAVIORS REGARDING SOCIAL SUPPORT AND COPING

by

Kristen Leigh Willett
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Committee:

_____ Director

_____ Department Chairperson

_____ Program Director

_____ Dean, College of Humanities
and Social Sciences

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by

Kristen Leigh Willett
Master of Arts
George Mason University, 2009
Bachelor of Arts
Christopher Newport University, 2007

Director: Anne Nicotera, PhD
Department of Communication
College of Humanities and Social Sciences

Summer Semester 2015
George Mason University
Fairfax, VA



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DEDICATION

This research is dedicated to my family. Without their love, guidance and support I would be lost. Thank you for all the times you listened and quietly nudged me forward in this endeavor. I would not have this degree without your support. This research is also dedicated to all those suffering from invisible illnesses. I hope that this research helps us all find ways to cope better.

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LIST OF ABBREVIATIONS

| Abbreviation | Page |
|--|------|
| Fibromyalgia | 1 |
| Centers for Disease Control and Prevention | 4 |
| American College of Rheumatology | 5 |
| Rheumatoid Arthritis | 6 |
| Restless Leg Syndrome | 7 |
| Post Traumatic Stress Disorder | 8 |
| Multiple Sclerosis | 14 |

ABSTRACT

A WIFE OR A PATIENT: FIBROMYALGIA PATIENTS' COMMUNICATION BEHAVIORS REGARDING SOCIAL SUPPORT AND COPING

Kristen Leigh Willett, PhD

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Dissertation Director: Dr. Anne Nicotera

The objective of this dissertation research is to explore how women with fibromyalgia (FMS) communicate about their illness with their spouse to receive social support and how that communication affects coping strategies. To better understand this phenomenon, a sequential exploratory method was used and the research was conducted in two phases: (1) qualitative interviews that utilized turning point graphs and a retrospective interview technique and (2) a quantitative survey based on the qualitative findings. Three research questions were posed during Phase 1: (RQ1) What turning points characterize women's experiences with FMS? (RQ2) What turning points characterize women's experience in finding barriers to and the need for support with a relational other? (RQ3) How are relational turning points associated with illness turning points? Analysis of the data found 4 themes in RQ1: first symptom, difficulty with medical community, flares, and finding coping strategies; and three themes in RQ2: guilt,

loneliness, and instrumental support. RQ3 analysis found little crossover between the turning point graphs. It was concluded that this was due to feelings of isolation and difficulty in communicating needs with their partner. From Phase 1, two additional research questions arose and were explored in Phase 2: (RQ4) How well do communication competence, perceived communication competence of partner, and relational satisfaction predict perceptions of social support? (RQ5) How well do communication competence, perceived communication competence of partner, relational satisfaction and perception of social support predict perceptions of coping with FMS? To answer these questions, the quantitative data were analyzed using stepwise multiple regressions. RQ 4 analysis found both perceived communication competence of the husband, in this case, and overall satisfaction with the relationship were highly significant predictors ($p < .000$) for social support (adj. $R^2 = 0.77$). RQ5 analysis found only communication competence to be a significant predictor of coping (adj. $R^2 = 0.09$). Finally, Equity Theory, Communication Privacy Management Theory, and the Relational Health Communication Competence Model were utilized to give meaning to the findings. A model describing of FMS Patients' Communication was developed.

CHAPTER ONE

Researchers have found that supportive communication plays a complex role in the course and experience of health and illness (Albrecht & Goldsmith, 2003). Burleson (2003) found that individuals who receive emotional support feel better, have better coping skills and may actually be healthier. Such research is important to the study of stigmatized illnesses because patients who suffer from these conditions often do not seek support and are not provided support in the ways needed to be beneficial. One such stigmatized illness is fibromyalgia syndrome (FMS).

Research on the FMS experience has predominately centered on the ways the disease affects the body and mind. For example, research on FMS has focused on the physiological effects the disease has on the patient in terms of pain (Hallberg & Carlsson, 2000; Söderberg & Lundman, 2001; Söderberg, Lundman, & Norberg, 1999; Sturge-Jacobs, 2002), fatigue (Cudney et al., 2002) and psychological problems (Bennett et al., 2007; Kelly & Clifford, 1997). Studies on FMS have also centered on the ways patients are diagnosed (Barker, 2005; Hallberg & Carlsson, 1998; Hellstrom et al., 1999; Paulson, Danielson, & Soderberg, 2002; Sturge-Jacobs, 2002) and how the invisibility of the disease causes issues with legitimacy (Barker, 2005; Cunningham & Jillings, 2006).

FMS researchers have also focused on individual coping strategies patients use (Cudney et al., 2002; Madden & Sim, 2006; Henriksson, Gundmark, Bengtsson, & Ek

1992; Miles, Curran, Pearce, & Allan, 2005; Raymond & Brown, 2000; Sturge-Jacobs, 2002). Examples of these coping strategies include the ability of the self to understand FMS (Madden & Sim, 2006; Raymond & Brown, 2000), engaging in positive thinking (Cudney et al., 2002) and how the patient re-evaluates his/her life (Henriksson, Gundmark, Bengtsson & Ek 1992). Yet, a much smaller number of research studies have discussed how patients with FMS communicate about the disease in the context of their interpersonal relationships (Hallberg & Carlsson, 2000; Kelly & Clifford, 1997) and even fewer studies have focused on how this communication leads to social support.

Problem Statement

Cline (2003) defines health communication inquiry as looking at the relationships between communication and health, health attitudes and beliefs, and health behaviors. Until recently, a large portion of the research in the field of health communication has focused on mass communication rather than interpersonal, and research that does focus on interpersonal communication concentrates mainly on the interaction between patient and health care providers (Cline, 2003). In order to expand our knowledge in the field of interpersonal communication as well as health communication, more health-related research should be performed on personal relationships such as family, partner, friends, and co-workers. One reason for research on personal relationships and health is best described by Thompson and Parrott (2003): “There is little other interpersonal research that can have the bottom-line impact of health communication” (p. 680). This study focuses on one portion of interpersonal communication by examining the how spousal communication functions in gaining social support.

FMS can be classified as an invisible illness which is defined as “one that is hidden so as not to be immediately noticed by an observer except under unusual circumstances or by disclosure from the disabled person or an outside source” (Matthews, 1994, p. 7). Social support is an integral aspect of human life and has a positive effect on both mental and physical well-being (Achat, et al., 1998; Cornman, Goldman, Gleib, Weinstein & Chang., 2003). Social networks provide members with emotional, psychological and instrumental support through shared communication (Achat et al., 1998). Past research shows that because of worry over stigma, people with invisible illnesses rarely disclose information concerning the illness unless circumstances arise that make it necessary (Matthews & Harrington, 2000; Merrigan, 2000). Because there is a greater lack of self-disclosure, finding social support may be more difficult for invisible illnesses sufferers than for those with visible illnesses. Past investigators have found that the quality of support rather than the quantity led to lower levels of depression, helplessness and mood disturbance and higher levels of self-efficacy (Franks & Cronan, 2004). Also Schoofs, Bambini, Ronning, Bielake, and Woehl (2004) found that individuals who are suffering from FMS do not experience high levels of social support. Finally, Juuso, Skar, Olsson, and Soderberg (2011) conclude that one reason women with FMS said they did not ask for help was due to others’ judgmental attitudes. Yet, much of the research on FMS focuses more on whether the patient is able to receive social support, rather than how they receive the support, whether it is helpful, and what types are helpful. The goal of this study is to understand how persons suffering from an invisible illness such as FMS find social support. By focusing on how FMS patients

communicate about their illness over time and how that communication leads to social support, greater understanding of this phenomenon can be acquired. This study is framed by naturalistic inquiry, uses a conceptual framework of turning point analysis to understand the role communication has in FMS patients finding social support, and uses a sequential exploratory method to better understand the phenomenon.

Defining Fibromyalgia (FMS)

FMS is classified as a chronic pain disorder. According to Weiner (2007), chronic pain is defined as pain that persists beyond the expected time of healing, which is normally four to six months. The American Academy of Pain Management reports that an estimated 116 million people in the United States live with chronic pain caused by disease, disorder or accident, as well as an additional 25 million who suffer from acute pain caused from surgery or accident (Institute of Medicine, 2011). Approximately two thirds of these individuals have been living with this pain for more than five years (Weiner, 2007).

The Centers for Disease Control and Prevention (CDC) (2015) characterizes FMS as a syndrome predominately characterized by widespread muscular pains and fatigue, and states that its causes are unknown. However, researchers hypothesize that genetics as well as physical and emotional stressors are possible contributory factors to the development of the illness. Additionally, the CDC states that FMS affected five million Americans in 2005. Women are identified as the majority of individuals who are diagnosed, with a ratio of seven women to one man in 2005. Furthermore, the majority of women who are diagnosed with fibromyalgia are between the ages of 20 and 50 (CDC,

2015). Wolfe et al., (1990) classifies fibromyalgia as chronic widespread pain and pain on palpitation of at least 11 of 18 tender points sited throughout the body and other symptoms of fibromyalgia are sleep disruption, fatigue, depression, anxiety, memory and concentration problems, headaches, and numbness or tingling. Bernard, Prince, and Edsall (2000) found that these symptoms have an immense impact on the patient's daily life, which limits patient's functioning and emotional well-being. There is no concrete diagnostic test for FMS, which creates difficulties for clinicians to recognize the illness. The physician may view the condition as a psychiatric disorder, or see the patient as exhibiting psychosomatic symptoms which can cause the patient to feel stigmatized due to his/her disease (Arnold et al., 2008).

FMS symptomology and comorbidities. In order to understand the how communication functions in gaining social support for FMS patients, it is important to understand the effects the disease has on the patient. FMS patients differentiate from other invisible illness patients for many reasons. One is that they are rarely experiencing only one or two symptoms and may also be diagnosed with another disease. Additionally, the most prominent symptoms of FMS, pain and fatigue, are rarely visible to doctors and support networks, which may affect how patients seek social support.

FMS has a variety of symptoms as well as comorbidities. In 1977, Smyth and Moldofsky listed the clinical manifestations of FMS as pain, fatigue, dysfunctional sleep, and tenderness. In an American College of Rheumatology (ACR) classification paper of FMS, Wolfe et al., (1990) listed additional symptoms that are more common, such as paresthesia, anxiety, headaches, irritable bowel syndrome, urinary urgency, sicca

symptoms (an autoimmune disease commonly called dry eye that affects both tears and saliva production), noise and cold intolerance, dysmenorrhea, depression, low back pain, and neck pain. In 2007, Bennett et al. conducted a survey of 2,596 FMS patients in which the researchers asked the patients to rank order their symptoms. They found that the top ten symptoms were morning stiffness, fatigue, nonrestorative sleep, pain, forgetfulness, poor concentration, difficulty falling asleep, muscle spasms, anxiety, and depression. While there are many different symptoms of FMS, there are also a variety of comorbidities or associated disorders that tend to occur as a symptom. According to Bennett (2007), a few comorbidities often found with FMS are insomnia, irritable bowel syndrome, overactive bladder, multiple chemical sensitivity, general depression, general anxiety, posttraumatic stress disorder, chronic fatigue syndrome, and restless leg syndrome. Also, FMS routinely occurs in conjunction with other illnesses such as Lyme disease, rheumatoid arthritis (RA), and lupus.

The core symptom of FMS according to the ACR classification criteria is chronic widespread pain. This is also the most highly studied aspect of FMS (Barker, 2005; Bennett et al., 2007; Cudney et al., 2002; Hallberg & Carlsson, 2000; Paulson, Danielson, & Soderberg, 2002; Raymond & Brown, 2000; Sim & Madden, 2008). FMS patients usually describe their pain as muscle or joint pain and tender skin (Bennett et al., 2007). The pain experienced is often ambiguous or conflicting in nature. At times the pain might be localized, and at other times it might be widespread and shifting (Hallberg & Carlsson, 2000; Söderberg & Lundman, 2001). The pain may also be both constant and varying (Cunningham & Jillings, 2006). Bennett et al. (2007) and Cudney et al., (2002) also

discussed pain “flares” that may occur after unaccustomed exertion, prolonged inactivity, soft tissue injuries, surgery, poor sleep, cold exposure, long car trips, the weather and psychological stressors. In one study, the participants discussed how the pain was both mental and physical (Paulson, Danielson, & Soderberg, 2002). This pain is hypothesized to be the one of the reasons the other common symptoms such as fatigue, sleep disorders, and depression are as severe.

The second most common symptom patients encounter is fatigue. While fatigue can be a symptom for many different illnesses, FMS patients usually describe their fatigue as an overall weariness that affects the mind and body and impairs their productivity and enjoyment in life (Bennett et al., 2007). Also, Cudney et al., (2002) found that while pain has a more dramatic impact on daily lives, some felt the fatigue was more debilitating. Three factors that may cause the fatigue are pain, depression and disordered sleep (Bennett et al., 2007; Hellstrom et al., 1999; Soderberg et al., 2002). Many FMS patients report disturbed sleep as a symptom as well as a contributing factor of fatigue. Ohayon (2005) found that FMS patients often have problems with sleep initiation and maintenance. Yet Stone et al., (2008) found that the biggest problem for FMS patients was feeling tired upon waking. They identify this problem as nonrestorative sleep and define it as a report of persistently feeling unrefreshed when waking after getting a normal amount of rest. Some causes for nonrestorative sleep are the comorbidities of restless leg syndrome (RLS) and insomnia. In a study by Stehlik, Arvidsson and Ulfberg (2008), in a sample of over 3300 women, 64% also had RLS, which is associated with periodic limb movement disorder.

According to Buskila and Cohen (2007), there is a general consensus that depression, anxiety disorders, and post-traumatic stress disorder (PTSD) are common in FMS patients. Epstein et al. (1999) conducted an investigation at four tertiary-care centers to determine psychiatric comorbidities for FMS. They found that people who were diagnosed with FMS showed high functional impairment, high levels of some lifetime and current psychiatric disorders, and significant current psychological distress. Kelly and Clifford (1997) also found that several factors were cited by participants for causing depression, examples being pain and fatigue. In another study, approximately 30% of patients with FMS have major depression at the time of diagnosis, and the lifetime prevalence of depression is 74% (Arnold et al., 2004). There have also been speculations about the nature of this relationship, including that FMS causes depression or vice versa. According to Fishbain et al., (2005), depression, as a consequence of the presence of chronic pain, is more common in chronic pain patients than in healthy controls.

In extreme cases, researchers found the FMS may lead to PTSD (Aghabeigi, Feinmann, & Harris, 1992; Muse, 1986; Sherman, Turk, & Okifuji, 1999). Geisser et al (1996) found that the presence of symptoms indicative of PTSD, regardless of PTSD diagnosis, seems to be related to greater problems in chronic pain patients. According to Sherman, Turk, and Okifuji (1999), 56% of FMS patients in the sample presented with significant levels of PTSD-like symptoms. They also found that the participants with significant levels of PTSD-like symptoms reported higher levels of pain, disability, and affective distress. Finally, they found that the patients who showed significant levels of

PTSD-like symptoms reported greater difficulty in coping and adapting to their pain. Yet the relationship between FMS and PTSD is still not fully understood. Some studies have revealed that PTSD patients may also be at a higher risk for developing FMS. A study by Amital et al. (2006) found that 49% of PTSD patients fulfilled the requirements for FMS, whereas only 5% of depression patients filled the same requirements.

FMS as stigmatizing. Various types of illnesses have been associated with stigma, which can be defined as an “attribute that is deeply discrediting” and reduces an individual “from a whole and usual person to a tainted and discounted one” (Goffman, 1963, p. 3). The stigmatization process is important in healthcare because it increases illness related stress, negatively affects treatment behaviors, contributes to patients’ psychological distress, and reduces social opportunities (Corrigan, 2004)

There are two main factors that cause FMS to be stigmatizing to patients: the process of being diagnosed and the nature of the illness. What makes FMS different from many other illnesses is that it is very difficult to diagnose and has a very intangible etiology (Sturge-Jacobs, 2002). This can enhance the stigmatization potential. According to Wolfe et al. (1990), the only testing method that can be used to diagnose FMS patients is a tender point test. This test is defined by the ACR criteria for FMS and includes 18 tender points, which are examined by manual palpation using a force of less than 4kg/cm, and asking the patient whether it resulted in pain. Originally Wolfe et al (1990) developed the tender point test to be used as an epidemiologic classification tool, yet necessity caused it to become useful for diagnosis as well as classification. Bennett et al. (2007) state that the tender point test is rarely performed in a primary care setting and is

only used by about 50% of rheumatologists in their routine practice; therefore a problem exists with performing the tender point test which requires training and experience that is lacking in most primary care settings.

Bennett et al, (2007) highlight the issues many individuals have in getting a FMS diagnosis. For many, the first doctor the patient, who is experiencing widespread pain, will see is located at a primary care facility. If the doctors in this facility are not adequately knowledgeable or trained in testing for FMS, the patients might have a difficult time receiving a correct diagnosis (Asbring & Narvanen, 2002; Bennett et al, 2007; Paulson, Danielson, & Soderberg, 2002). Research discovered that for many patients with FMS, medical personnel would trivialize their subjective experience or believe the patient was suffering from a psychosomatic condition rather than a physiological condition (Cooper, 1997; Henriksson, 1994; Sturge-Jacobs, 2002). Charmaz (1983) states that when a patient does not display any external signs of illness and the tests do not show abnormal results, a caregiver may regard the patient as someone who is simulating illness or is mentally ill. Asbring and Narvanen (2002) found that when a doctor dismisses the illness as irrelevant or psychosomatic this has a highly stigmatizing effect on the patient who is actually suffering from FMS. Some of the women in the study felt the doctor, without carrying out proper examinations, categorized their problem as fictitious or related to psychological reasons. To these women, this experience was deeply violating.

Another reason FMS causes patients to feel stigmatized in their everyday lives is due to its invisible nature (Asbring & Narvanen, 2002; Hallberg & Carlsson, 1998;

Henriksson, 1994). Asbring and Narvanen (2002) discuss how participants felt challenged by others regarding their experience of being ill which was mostly caused by the absence of any visible external signs of the illness. Barker (2005) found many of the participants believed that if they had external symptoms, it would have enhanced their credibility. Asbring and Narvanen (2002) also found that the diagnosis itself also caused stigmatization. While the patients felt the diagnosis was very important in regards to legitimizing their problems, the characteristics of the disorder can also hold certain implications for stigmatization. They found that the participants felt that other people would depreciate FMS as being a woman's condition, which may lack legitimacy with caregivers.

Impacts on relationships. FMS patients must find strategies to cope with the stigma they experience and various studies have found that this impacts quality of life (Bernard, Prince, & Edsall, 1999; Burckhardt, Clark, & Bennett, 1993; Bennett et al., 2007; Ryan, 1995). Asbring and Narvanen (2002) discuss ways in which their participants handled the stigma they felt due to FMS. People with chronic illnesses strive to be seen as a full member of society where they are accepted by others. In order to do this, their participants had specific strategies that included keeping a distance from others and concealing information. According to Asbring and Narvanen (2002), patients with FMS would withdraw in order to avoid the demands and expectations from others as to how one ought to be. Schaefer (2005) also found individuals would keep the diagnosis a secret to manage the stigmatization. FMS symptoms themselves can cause patients to withdraw because it affects patients' ability to establish and maintain emotional and

physical contact with those around them. Also, Asbring and Narvanen (2002) found participants described avoiding people who had previously acted negatively towards them and their illness to avoid being exposed to stigma. One remarkable finding was that while these women in the study did withdraw from some individuals, they compensated with a greater intimacy with others who understood their illness. Arnold et al (2008) found that participants had a hard time planning events because they were not able to predict how they would feel. The participants also reported being reluctant to commit to social activities and feelings of worry that others were judging them as being unreliable.

Another strategy Asbring and Narvarnen (2002) observed was that some women would try to manage the situation best by participating in activities instead of withdrawing from them. In order to participate in activities, the participants would conceal the illness by putting on a façade. The participants discussed how at social gatherings they would sometimes play up the identity of a healthy, happy, normal person. But this façade would strain them to the point of almost collapsing with fatigue and pain when they arrived home. On the other hand, this façade would minimize the negative judgments of others about their illness, and they could more easily maintain their earlier identity.

Patients with FMS also have a hard time engaging in family and work duties. One of the largest impacts of fibromyalgia was the burden the disease placed on their spouses and partners because they had to take on a greater share of chores, childcare, and other responsibilities (Arnold et al., 2008; Cudney et al., 2002; Henriksson 1994). Arnold et al also found that participants reported having to frequently change jobs or take a

reduction in hours due to the inability to perform some tasks. All but one of Wuytack and Miller's (2011) participants had to quit working due to FMS. Yet, Arnold et al (2008) found approximately half of their participants had stopped working altogether. This had an impact on their mental well-being as well as their identity. They also found that their jobs gave the participants satisfaction in both accomplishing goals and in helping to create a normal identity. They also discovered many of the participants discussed how it was extremely frustrating for "driven" women to be unable to operate at their previous capacity. Kelly and Clifford (1997) concluded that a loss of former identity was strongly linked with the loss of job and the inability to pursue long-term career interests. Not only did FMS affect ability to work outside of the house, but it also affected ability to perform daily living tasks such as self-care and household chores, as well as leisure activities (Arnold et al, 2008; Wuytack & Miller, 2011).

Social Support and FMS. Social support is a term referring to interpersonal relationships that are beneficial to a person's well-being (Cohen, & Syme, 1985; Smarr et al., 1997; Uchino, 2006). Cohen and Syme (1985) defined social support as the resources provided by other persons. Social and emotional support can increase personal competence, perceived control, sense of stability and recognition of self-worth (Krause & Shaw, 2000; Langford, Bowsher, Maloney, & Lillis, 1997) and a positive effect on quality of life (Helgson, 2003). Studies have shown that individuals with low levels of social support have higher mortality rates from illnesses such as cardiovascular disease (Brummett et al, 1998; Frasure-Smith et al, 2000; Rutledge et al, 2004). Researchers have discovered a link between social and emotional support and less risk of mental and

physical illness, and mortality (Achat et al, 1998; Berkman, 1995; Hale, Hannum, & Espelage, 2005; Lyyra & Heikkinen, 2006; White, Philogene, Fine, & Sinha, 2009).

Social support is also positively associated with subjective well-being and functional health status in people with chronic rheumatic disorders (Fitzpatrick, Newman, Archer, & Shipley, 1991; Goodenow, Reisine, & Grady, 1990). Research by Smarr et al. (1997) on rheumatoid arthritis has shown that positive social support has been linked to improved adherence to medical regimens and better rehabilitation outcomes. In contrast, poor social support has been linked to decreased psychological adjustment and less effective coping skills. Studies on FMS have shown that the perception of adequate social support is a key factor in health outcomes. In some cases the actual amount and type of social support appears to be less important than the perception of the adequacy of social support, and there is a large margin of variability across persons about the amount and type of social support perceived as adequate (Schoofs et al, 2004). This suggests that research needs to be conducted to understand the support patients perceive as adequate.

Research on social support and FMS has also explored social support within the family unit. In research by Bernard, Price and Edsall (2000) participants rank ordered the social support received from various family members. The mean ranking was highest for the patient's significant other and children. It was also higher for female relatives than for male relatives. Research on multiple sclerosis (MS) and social support found that living with a spouse, followed by employment, was the most important of six demographic domains related to quality of life, and spouses were ranked highest in offering social support (Gluick, 1994). Also, according to Franks, Cronan, and Oliver (2004) when

assessing depression, helplessness, mood disturbance, quality of well-being, and impact of FMS, being satisfied with one's social support network appears to be more important than the size of the support network for women with FMS.

Importance of Study

As seen throughout this chapter, there is a greater body of research on how FMS affects the body in both physiological and psychological ways. Research on FMS has also concentrated on the difficulty patients have during the diagnostic process and the lived experience of FMS. There is little research, however, on how these experiences affect the ways patients communicate with others about the disease and how this communication affects social support. Recent literature on invisible illnesses and the lived experience of FMS reveal the invisibility of FMS to be a significant factor in the FMS experience and the relative dearth of a connection to social support or to the communication dynamics of seeking such support (Raheim & Haland, 2006; Schaefer, 2005; Wuytack & Miller, 2011).

Research centered on invisible illnesses has focused on the impact of identity, disclosure regarding the illness, and stigma (Horan et al., 2009; Keigher & Jurkowski, 2001; Kundrat & Nussbaum, 2003). A patient's identity may be affected by an invisible illness. One study found that patients with cardiovascular disease had greater ages on the contextual age questionnaire than healthy demographically matched individuals (Kundrat & Nussbaum, 2003). This may be due to others' surprised reactions to the disclosure of the illness, the change in others' behavior, and expressions of concern. Disclosure of invisible illness has additional effects on the patient as well. In a study by Horan et al

(2009), the researchers asked participants if they would want to establish a relationship with an individual with cancer or an individual with HIV. They found that participants were less likely to want to forge a relationship with an HIV patient and more likely to forge a relationship with a cancer patient. This study shows that illness stigma may play a role in relationship development, which may explain why patients with stigmatized invisible illnesses are less likely to disclose information about the illness. According to Joachim and Acorn (2000), “When visible, the individual has options but they are limited. When invisible, there are more options and a person may pass if he is successful in hiding the condition, or experience stigma if he discloses or is caught in a lie while attempting to pass as healthy” (p. 247). This suggests that in addition to coping with the disease, a person with an invisible illness must also make complex decisions about to whom they will reveal the illness.

Recent research on FMS has centered on symptomology (Bennett et al., 2007; Cudney et al, 2002; Hallberg & Carlsson, 2000; Kelly & Clifford, 1997; Söderberg & Lundman, 2001) diagnostics (Barker, 2005; Hallberg & Carlsson, 1998; Henriksson, 1995; Madden & Sim, 2006; Paulson, Danielson, & Soderberg, 2002; Sturge-Jacobs, 2002), and the effects the disease has on the patient emotionally and socially (Arnold et al, 2008; Asbring & Narvanen, 2002; Buskila & Cohen, 2007; Epstein et al, 1999; Kelly & Clifford 2007; Sturge-Jacobs, 2002). FMS researchers have examined doctor patient interaction (Crooks, 2007; Thorne, McGuinness, Con, Cunningham, & Harris, 2004), patients’ and caregivers’ experiences (Rodham, Rance, & Blake, 2010) to the ways in which the patients create meaning from the illness (Madden & Sim, 2006; Söderberg,

Lundman, & Norgerg, 2001), and studying lived experiences of FMS patients (Raheim, Haland, 2006; Shaefer, 2005; Wuytack & Miller, 2011). Although only a few of these FMS researchers use the terminology “invisible illness,” the invisibility of the disease is a central feature in most works on the subject.

In a meta-analysis of 23 published articles on FMS, Sim and Madden (2008) found the most widely studied aspect of FMS was pain and the ways patients make sense of and describe it (Cudney et al., 2002; Madden & Sim, 2006; Paulson, Danielson, & Soderberg, 2002; Schaefer, 1995). The second most studied topic was diagnosis and the difficulty patients have when seeking medical help (Barker, 2005; Hallberg & Carlsson, 1998; Henriksson, 1995; Kelly & Clifford, 1997; Schaefer, 1995; Sturge-Jacobs, 2002).

Because FMS is invisible, there is a dissonance between the individual’s appearance and the ability to participate in activities, which causes work colleagues, health care professionals, and even family members to question the illness (Barker, 2005; Cunningham & Jillings, 2006; Kelly & Clifford, 1997; Sturge-Jacobs, 2002). Researchers have also found that patients felt betrayed and discredited because health professionals can give no effective disease management, and FMS patients feel extremely stigmatized by practitioners who did not understand the illness (Thorne et al, 2004). Also, receiving a formal diagnosis does not fully alleviate problems with legitimacy. Madden and Sim (2006) found that initially a formal diagnosis gives the patient legitimacy because it validates how they are feeling; yet many still had difficulty explaining the illness to their social networks who had rarely heard of FMS. The issue of legitimacy could be seen as a barrier to finding social support, but this link is seldom discussed in the research. This

dissertation research will contribute to the previous work on this topic because it will closer examine the link between legitimacy and communicating about the illness to find social support.

Previous studies discovered that living with FMS means an existential breakdown of the familiar world. Loss of bodily-based integrity, control, and the freedom to act forces patients to find coping strategies to manage the illness. Studies on coping and FMS have found patients use strategies such as becoming a self-advocate and seeking information (Raymond & Brown, 2000; Schaefer, 2005; Söderberg, Lundman, & Norberg, 1999); engaging in positive thinking (Cudney, Butler, Weinert & Sullivan, 2002; Lofgren, Ekholm & Ohman., 2006), resisting the dominance of symptoms (Thorne, et al., 2004), and finding distraction in pleasurable activities (Hallberg & Carlsson, 1998, 2000; Schaefer, 1995). FMS patients must also cope with the illness by struggling to maintain a balance between pushing the limits and preventing the body from becoming too exhausted (Barker, 2005; Cudney et al., 2002; Raheim & Haland, 2006). Some patients would cope with this balance by planning activities and using carefully structured daily routines (Hallberg & Carlsson, 1998). An extremely important coping strategy is the ability for the patient to understand how FMS affects them. This involves becoming aware of the symptom patterns, listening to one's body, and developing the ability to reflect upon oneself and accept the losses from the illness (Madden & Sim, 2006; Raymond & Brown, 2000). Only a small number of articles have looked at the use of social or family networks and support groups to help the patient cope with FMS (Kelly & Clifford, 1997; Rodham, et al., 2010). Rodham, et al. (2010) found that FMS patients

experienced role changes due to the illness and that participants lost social lives because of the symptoms. Spousal caregivers discussed how their wives were no longer the same and felt their marital relationship was fundamentally altered as well. While researchers have focused on coping, it has primarily focused on the individual coping strategies, rather than relational and social coping strategies, but research shows that coping with stressful life events is also a social process (Lyons, Jones, Bennett, Hiatt, & Sayer, 2013). Therefore, while individual coping strategies are important to understand, researchers must also focus on the coping strategies used with relational partners, such as asking for help, understanding, and support. This study will attempt to understand how social support helps FMS patients cope with the disease by examining instances when they sought support from a relational partner.

Previous investigations to find links between social support and FMS have largely been focused on the lived experience of FMS. For example, in studying the lived experience of African American women with FMS, researchers have found that participants keep their experience with the illness a secret from their families and friends (Schaefer, 2005). The reason the women limited disclosure about the illness was due to others' reactions, misunderstandings, or a fear of burdening others. Other research on the lived experience of FMS has found that support from family was extremely important in helping the patient cope with the disease (Wuytack & Miller, 2011). Additionally, Rodham, et al. (2010) discovered that the FMS patient and the spousal caregiver had different means of coping with the illness. Caregivers would direct their anger at the health care system and the illness, whereas FMS patients would try to maintain a level of

normalcy in order to cope with the disease. This pattern may be maladaptive to the patient because by maintaining a level of normalcy, they are not actively seeking support, which may lead to feelings of loneliness and isolation. As seen here, there is a wide array of findings regarding FMS and social support. This could be partially due to the samples used or to the lack of focus on support as most of these studies were simply focused on the overall lived experience. In order to expand on the current research, studies need to focus explicitly on the effects FMS has on finding social support. Researchers must seek to understand communication about FMS and how everyday interpersonal communication may help to mitigate the emotional and physical pain associated with FMS.

Social support plays a key factor in health outcomes (Schoofs et al., 2004). Yet, the current body of research on FMS has largely been focused on investigating its causes, prevalence, and incidence through the use of questionnaires. While studies have captured the women's own stories of their experiences with FMS, few have used the data to find information about social support seeking behaviors. This study serves as a step towards understanding how FMS patients communicate about their illness over time, and how that communication leads to social support.

Conceptual Framework

Mixed methods: Sequential exploratory. Because this research is interested in understanding both the lived experiences of FMS patients in regard to social support seeking behaviors and understanding how these behaviors lead to coping with the disease, a sequential exploratory method was used. In this mixed method approach, a two

phase research study was performed. In the first phase, qualitative data were gathered through naturalistic inquiry. This phase focused on the turning points in the participant's experience with the disease as well as the turning points in the relationship between participant and spouse. A phenomenological thematic analysis was performed and from these data a quantitative questionnaire was designed to focus on communication competence, perceived communication competence of partner, relational satisfaction, social support, and coping.

Phase 1: Naturalistic Inquiry. This research phase focuses on how FMS patients find social support over time and will follow a naturalistic inquiry. Specifically, the study seeks to understand FMS patients' experiences in disclosing illness, seeking social support, and receiving/using that social support. The best way to understand this is through a naturalistic inquiry that privileges the voices of participants in making sense of their own experiences.

Naturalistic inquiry (Lincoln and Guba, 1985) is based on five axioms. The first axiom, or ontology of naturalistic inquiry, posits that there are multiple intangible realities, which should be studied holistically. Also in order to identify the multiple realities, data analysis should be inductive. Such analysis needs to make the investigator-respondent interaction explicit, recognizable, and accountable as inductive data analysis is more likely to identify the mutually shaping influences that interact (Lincoln & Guba, 1985). Because each person creates his or her own understanding of the concept, it must be dealt with in a holistic fashion. Inquiry into these multiple realities will inevitably diverge as there is no common or typical reality of the concept, and each inquiry will

raise more questions than it will answer. This is one main reason why naturalistic inquiry is useful to this study. Many have looked at the lived experience of FMS (Radheim & Haland, 2006; Rodham, Rance, & Blake, 2010; Söderberg, Lundman, & Norburg, 2001; Schaefer, 2005; Wuytack & Miller, 2011) and, precisely because they viewed it through a naturalistic lens, were able to reveal that there is no common reality. For example, Schaefer (2005) found family as unsupportive, while Wuytack and Miller (2011) found family extremely supportive. Also while these studies have looked similar concepts, they have led to further questions, upon which this research will focus. In this type of inquiry, the goal is to achieve understanding rather than predictions.

The second axiom of naturalistic inquiry is that the researcher and the participant will interact and may influence each other (Lincoln & Guba, 1985). Just as the inquirer may shape the respondent's behavior, the respondent may also shape the inquirer's behavior. Yet, instead of trying to reduce respondent and inquirer interactivity, the naturalist uses it as a tool in the research process. The presence of interactivity makes it possible for the researcher to be a "smart" instrument by honing in on relevant facts and adapting. Being a smart instrument includes using the human as the primary data collection instrument and using it to the fullest of its capabilities. Through using the researcher as the instrument, he or she can build upon tacit knowledge, intuitions, and apprehensions that occur to inquirers through training and experience. For this research, my training and experience as a researcher will serve as useful during the interview process. Further, my personal experience with a similar chronic pain disease provides a tacit understanding of the experiences I seek to explore. My own experience with chronic

pain will also introduce biases, which I bracket in Appendix A based on a description of my standpoint. However, both tacit knowledge and credibility enhance my ability to make the most of respondent-inquirer interactivity as it provides a valuable credibility with respondents in my status as an in-group member.

Another axiom of naturalistic inquiry focuses on generalizability. According to Lincoln and Guba (1986) statements cannot be made about human phenomena that are likely to be true for a substantial number of years or any substantial contexts. They also state that the naturalist should first be concerned with developing an adequate idiographic statement about the situation he or she is studying and use thick descriptions when making judgments about transferability. The fourth axiom of naturalistic inquiry focuses on explanation of actions. In this axiom, a naturalist inquirer sees actions emerge through a simultaneous shaping rather than a cause and effect relationship. In regards to this research, it is important to remember that the barriers to social support are not simply the effect of a difficult diagnosis process, or a lack of understanding by a friend. Both of these conditions, in addition to many others, may play a role in FMS patients' difficulty in finding social support. This research focuses on understanding the simultaneous shaping occurring in the participants' lives to better understand the experience. Only then can the findings be examined for transferability.

The final axiom addressed by Lincoln and Guba (1986) discusses the values in inquiry. Where rationalists feel research is value-free, naturalists assume that research is value-laden and that inquiry is grounded in the value systems that characterize the researcher, participants, methodology, paradigm, and social and contextual concepts.

While rationalists see values as something to be put aside in research, naturalists acknowledge and take into account these values. Naturalists may also use methodological hedges such as bracketing to compensate for their intrusion. By bracketing, researchers can better understand their biases and attempt to place them aside during the data collection and analysis. As stated in Chapter 3, I perform my own bracketing on FMS and support.

Turning points. In order to better understand the relationship between communicating about FMS and social support over the course of the disease, a modified turning point analysis is used. Turning points can be used as a way to understand fluidity and change across time (Baxter 2004). The concept of turning points was first discussed by Bolton (1961) in a study examining marital dyads. Bolton focused on interpersonal processes that occurred over time. Turning points are events or relational incidents that are associated with change, and the use of turning points allows researchers to study relationships and experiences from a process point of view (Baxter & Bullis, 1986; Johnson, Wittenberg, Villagran, Mazur & Villagran, 2003).

To date turning point literature has been used to understand relational development (Bolton, 1961; Baxter & Bullis, 1986; Huston, Surra, Fitzgerald, & Cate, 1981; Surra & Hughes, 1997), organizational identification (Bullis & Bach, 1989), and illness identity development (Karp, 1994; Karp & Tanarugsachock, 2000). Many studies that focused on relational development have been interested in the ways in which significant events mark change in relational outcomes such as emotional closeness, commitment to the relationship and chance to marry the partner (Baxter & Bullis, 1986;

Surra & Hughes, 1997). The majority of this research has centered on dyadic relationships by focusing on how individuals perceive, construct, and are congruent with romantic partners, friends, parents, and mentors (Baxter & Bullis, 1986; Barge & Musambira, 1992; Bullis, Clark, & Sline, 1993).

Few articles have moved beyond the dyad by focusing on organizational identification or illness identification. Bullis and Bach (1989) focused on individuals' socialization experiences to an organization. This research found that newcomers are actively involved in perceiving, evaluating and managing their relationship with the organization. Karp (1994) focused on turning points in illness identification. This research found that patients with unipolar depression experienced specific turning points with the disease. Key points in their relationship with the disease involve having unclear feelings of distress, coming to feel something is really wrong, having a crisis, and coming to grips with the illness identity. While a focus on illness identity is helpful to understanding an internal coping process, it can also be explicated to understand how this process affects external coping processes such as social support.

Fisher (2010) used a turning point analysis to discover how the bonds between mothers diagnosed with breast cancer and their daughters changed over the life course of the illness. Fisher found that listening, showing affection, and using humor were common adaptive social support responses. This pattern differs for women diagnosed in midlife and their adult daughters. The mothers needed to feel their daughters were willing to talk, but the daughters had a tendency to withdraw. The daughters did this to protect themselves and were worried that discussing the illness would be more distressing. A

focus on the two turning point graphs of illness experience and relational communication about the illness might provide new insight as to how patients with a chronic disease, like FMS, seek social support throughout the course of the disease. By plotting two distinct graphs, the relationship between illness experience and relational communication can be seen. By examining how the two lines converge and diverge, we might understand how turning points in social support correspond with illness events.

Phase 1 research questions. Burleson, Albrecht, Goldsmith and Sarason (1994) state that social support “should be studied as communication because it is ultimately conveyed through messages directed at one individual to another in the context of a relationship that is created and sustained through interaction” (p. xviii). Also, Burleson and MacGeorge (2002) argue that through the interview process, participants can provide retrospective self-report data about helpful and unhelpful messages they have received from others. A retrospective interview technique will be used to acquire turning point data. The use of a turning point technique is appropriate when asking people to recall retrospective information when participants remember highly accurate turning points (Miell, 1984). Thus, the following research questions drive this study:

RQ1: What turning points characterize women’s experiences with FMS?

RQ2: What turning points characterize women’s experiences in finding barriers to and the need for support with a relational other?

RQ3: How are relational turning points associated with illness turning points?

Phase 2: Quantitative inquiry. Analysis of the interview data revealed five key variables: communication competence, perceived communication competence of partner,

relational satisfaction, social support and coping. The identification of these variables as key indicators of social support and coping produces two additional research questions:

RQ4: How well do communication competence, perceived communication competence of partner, and relational satisfaction predict perceptions of social support?

RQ5: How well do communication competence, perceived communication competence of partner, relational satisfaction and perception of social support predict perceptions of coping with FMS?

A 62 item questionnaire was developed in order to answer these questions and multiple regression analyses were performed.

Overview of the Study Rationale

FMS is a highly stigmatized condition due to two main factors: its invisible nature and the difficulty of diagnosis. The first stigmatizing factor lies in the invisible nature of the illness. Asbring and Narvanen (2002) discuss how their participants felt challenged by others regarding their experience of being ill, which was mostly caused by the absence of any visible external signs of the illness. Many of the participants believed that external symptoms would have enhanced their credibility. FMS cannot be proven by scientific means and is thus surrounded by uncertainty, enhancing the stigmatization potential. According to Wolfe et al. (1990), the only testing method that can be used to diagnose FMS patients is the tender point test. Within the medical community there are many who do not believe the tender point test is reliable. Cooper (1997) found that because they were not adequately trained in diagnosing FMS medical personnel would often trivialize

FMS patients' subjective experience or believe the patient was suffering from a psychosomatic condition rather than a physiological condition. When a patient does not display any external signs of illness and tests do not show abnormal results, a caregiver such as a doctor may regard the patient as someone who is simulating illness or is mentally ill (Charmaz, 1983). A doctor's dismissal of the illness as irrelevant or psychosomatic has a highly stigmatizing effect on the patient who is actually suffering from FMS (Asbring & Narvanen, 2002). Another cause of stigma for FMS patients is the co-morbidity of psychological illnesses. Approximately 30% of patients with FMS have major depression at the time of diagnosis, with the lifetime prevalence of depression at 74% (Arnold, et al., 2004). Many researchers have looked into the relationship between FMS and depression due to its prevalence in this community. There have been speculations about the nature of this relationship, including whether FMS causes depression or vice versa. This phenomenon needs further study to better understand how FMS as a stigmatized illness impacts communication with a relational other. In this study, the research focused on how women with FMS communicated regarding the illness with their spouse which includes methods for seeking social support, finding coping strategies, and what types of support were seen as most helpful.

Chapter Summary

While a variety of studies have focused on FMS, most have looked at the symptomology and prevalence of the disease. Fewer studies have focused on the aspect of social support and how it affects patients with FMS. Extremely few have researched social support-seeking through a communication lens. This study focuses on the social

support experiences of women with FMS. In Chapter 2, a review of literature regarding topics germane to this study is provided. A discussion of the psychological stress of FMS diagnosis and how this leads to stigma, the effects of stigma on self-disclosure, and the impacts of invisible illness follows. Finally, the types of social support and how it has traditionally been measured is offered.

The review of literature in Chapter 2 provides background information related to the research questions posed in this chapter. In Chapter 3, an outline of the qualitative and quantitative methods used to answer these questions is provided. Findings are discussed in Chapter 4. Finally, in Chapter 5, a discussion of the findings, limitations and strengths of this study, and recommendations for future research are provided

CHAPTER TWO

This chapter explores the literature associated with stigma, coping and social support as it relates to chronic illnesses and specifically FMS. Particularly, this chapter discusses how diagnosis of a stigmatizing illness affects a patient's abilities to cope and find social support. Historically, research reveals that social support has a great impact both psychologically as well as physiologically (Cobb, 1976; Cohen & Syme, 1985; DiMatteo, 2004; Thoits, 1998). Individuals who receive quality support from their relationships are more likely to have reduced stress and are more likely to make significant strides to recovery. This chapter addresses not only the effects of social support but also the types of support previous research has discovered to be helpful. Because social support requires open communication between the sender and receiver, research focused on this topic will also be discussed. Additionally, the literature reveals that not all social support is perceived as helpful, so it is important to understand the distinctions between the two and the effects of unhelpful support on communication. Finally, this chapter introduces the types of support and the types of coping as they are seen in participants with chronic illnesses.

Stress of the Diagnosis, Illness and Stigma

Stress plays an important role in the experience of FMS. As discussed earlier, the diagnostic process and the illness symptomology have a significant impact on patients

with FMS as many patients have a difficult time acquiring a diagnosis and coping with debilitating symptoms of the illness. Both of these factors cause stress in patients' lives. FMS also has high co-morbidity rates of a secondary invisible illness such as depression, post-traumatic stress disorder, and chronic fatigue disorder to name a few. For many, these factors and others often cause the patient to feel stigmatized and have higher levels of stress.

Bair, Robinson, Katon, and Kroenke (2003) performed an analysis of past research on pain and depression and found that when the presence of pain is moderate to severe, impairs function, and/or is refractory to treatment, it is associated with more depressive symptoms and worse pain outcomes. Also depression in patients with pain is associated with more pain complaints and greater impairment. Dailey, Bishop, Russell, and Fletcher (1990) found that FMS patients have higher levels of stress as measured by daily "hassles" than either RA patients or the control group. Gormsen, Rosenberg, Bach, and Jensen (2009) found FMS patients had significantly more mental distress including depression and anxiety than did healthy controls. They also found an association between pain and mental symptoms in FMS patients. Researchers have also found a correlation between higher stress and worse disease symptoms in patients with MS (Sorenson, Janusek, & Mathews, 2002). Finally researchers have discussed whether psychological stress leads to disease and the association between stress and four diseases: depression, heart disease, HIV/AIDS, and cancer. While there is still inconsistency concerning a causal link between stress and disease, it is an important factor in certain diseases (Cohen, Janicki-Deverts, & Miller, 2007).

Psychological stress also effects the regulation of immune and inflammatory processes and has the potential to influence depression as well as infectious, autoimmune, and coronary artery diseases (Cohen, Janiki-Deverts, & Miller, 2007). There are direct correlations between perceived stress and disease symptoms in patients with MS (Dailey, Bishop, Russel, & Fletcher, 1990; Sorenson, Janusek, & Mathews, 2002). Researchers have shown that FMS patients showed higher levels of stress in both daily hassles and overall life stress. The medical community (e.g. Van Houdenhove & Egle, 2004) still questions whether FMS is a stress disorder rather than a nerve/rheumatologic disorder. Van Houdenhove and Egle argue that there is a recursive causal relationship between FMS and stress. On one hand, FMS patients deal with emotion and conflict in maladaptive ways (Nickel et al., 2001; Zautra, Fasman, Parish, & Davis, 2007), which may explain one role stress plays in the FMS experience. For example, research found that FMS patients experienced an increase of pain after exposure to an interpersonal stressor, whereas women with osteoarthritis had no change (Murray, Daniels, & Murray, 2006). On the other hand, the symptoms lead to increased stress. These two factors can cause the patient to become trapped in a vicious cycle.

In addition to more stress, FMS patients are more likely to be diagnosed with a stigmatized co-illness, such as depression or PTSD. Links between mental illness and FMS have been found. Research shows that patients with FMS have a high lifetime and current prevalence of depressive and anxiety disorders (Aaron et al., 1996). Self-report scales show significant elevations in scores of depression, anxiety, neuroticism, and hypochondriasis (Epstein et al., 1999). Amir et al., (1997) found a prevalence of PTSD in

the FMS group at 21% vs. 0% in the control group. Sherman, Turk, Okifuji (2000) found that 56% of the sample of 93 FMS patients reported clinically significant levels of PTSD-like symptoms. Also the patients with PTSD symptoms reported significantly greater levels of pain, emotional distress, life interference, and disability. According to Cohen et al. (2002), patients with FMS and PTSD show greater levels of avoidance, hyper arousal, re-experiencing, anxiety, and depression. They also found that FMS patients with PTSD were more likely to use suppression style coping skills than minimization, help-seeking, replacement, blame, substitution, mapping, and reversal.

Stigma caused by the FMS and its co-morbidities may also cause stress. The extent to which a stigmatized person is denied positive life experiences and suffers from more of the negative is a source of chronic stress (Link & Phelan, 2006). Chronic stress has negative effects on both mental and physical health. According to Link and Phelan, the stress associated with stigma can be particularly difficult for people with disease-associated stigma because they are at risk for other stress-related illnesses, and the illness itself may be worsened because they may avoid both medical and interpersonal support. This can be seen in FMS research. Researchers have found that the effort made by people with FMS to hide their illness due to stigma and manage their self-presentation is partially responsible for others' failures to see their illness (Asbring & Narvanen, 2002; Rodham, Rance, & Blake, 2010; Söderberg & Lundman, 2001). Similarly, Hale et al., (2005) found that women reported "appearing to be well and actively working to do so" (p. 534) was problematic because they had trouble accessing support. The inability to find support led to social and physical isolation.

Invisible Illness and Communication

Some illnesses, such as cancer and epilepsy, can be either visible or invisible based on the cyclical nature of their symptoms. Conversely, illnesses such as depression and FMS are continuously invisible because they do not create any physically visible symptoms. Harrington and Matthews (1997) found that invisible illnesses are not only closely linked to a person's identity but can cause individuals to experience feelings of shame. In the study, individuals with an invisible illness usually did not disclose unless they were forced to for practical reasons. Also, many felt that if they did disclose information about their illness, they would receive unwanted sympathy and possibly damage existing relationships. Finally, participants in this study worried about whether people would believe them if they self-disclosed about an illness that is not seen (Harrington & Matthews, 1997).

Two factors play a role in understanding invisible illness. The first is that invisible illnesses are intertwined with social identity (Kundrat & Nussbaum, 2003). Identity is formed through social interaction, thereby causing individuals to form and accept their identities based on the world around them. If an individual has a chronic illness, not only are they more likely to be more aware of their identity because some may feel the need to conceal it, but they have more control over their identity as well (Kundrat & Nussbaum, 2003; Matthews & Harrington, 2000).

The second factor to understand about invisible illnesses is their association with negative social stigma (Matthews & Harrington, 2000). Goffman (1963) defines stigmatizing as a process in which a social meaning is attached to behaviors or individuals. The stigma associated with disease and disability provides a strong reasoning for a patient with an invisible illness to keep the disease concealed (Matthews & Harrington, 2000). Eventually though, the patient can accept the stigma and move into the culture of his/her disability (Braithwaite, 1990). Braithwaite conducted research on subjects who were clinically deaf and found that the interviewees eventually adopted a new culture that incorporated an identity as a disabled individual. Unfortunately, it is very hard for a patient with an invisible illness to assimilate to a new culture because the illness allows the patient to act as though they are members of the mainstream culture (Matthews & Harrington, 2000). As stated before, these subjects fight the paradox between “discredited” and “discreditable” persons (Goffman, 1963), where a discredited individual believes their disability is not only visible, but that they must manage anxiety caused by the visible illness. A discreditable person believes their disability is invisible and will try to attempt to keep their illness information concealed.

Some patients with invisible illnesses see their disabilities as an extremely private aspect of their identity due to factors such as shame and judgment (Coupland, Coupland, Giles, Hennwood, & Wienmann, 1988). Because of this, the level of disclosure is extremely high. The researchers call this type of disclosure “painful” because it is so personal and is perceived as a negative type of disclosure. In their study, they focused on the elderly and self-disclosure and found that types of painful disclosures included topics

of bereavement, ill-health, loneliness, family disputes, immobility, financial or social troubles and disengagement. Keeping the illness a secret can have many negative impacts on the disabled individual, and the symptoms may start to become more visible. Some illnesses can give off clues, which Goffman (1963) calls “leakage.” Goffman writes that many people will spend a large amount of time and energy on keeping the invisible illness undisclosed. In his research, he found that people use three methods to avoid leakage; they may attribute the signs of their disability to something not caused by a disability, they may avoid public situations when the leakage occurs, or they may avoid engaging in behavior where the leakage will become prominent. This too has been discussed in FMS research. Rodham, Rance and Blake (2010) observed that the women in their study spent considerable time and energy to conceal their illness. The participants would pace or curtail activity as a way to conceal and cope with FMS.

Open communication and avoidance. As previous researchers have documented, patients with invisible illnesses have a difficult time disclosing information about their disease. Therefore, patients with invisible illnesses must make decisions regarding when to use open communication and when to avoid communication about the illness.

Open communication is the disclosure of feelings, thoughts and information (Goldsmith, Miller, Caughlin, 2009). Porter, Keefe, Hurwitz, and Faber (2005) define open communication as patients’ and partners’ disclosures to one another regarding their fears, emotional issues, and doubts. At the other end of the spectrum is the avoidance of communication. A patient uses avoidance of communication when deciding to not

discuss an issue or to withhold some details of information. Scholars have studied and theorized the relational tensions between openness and closedness (Baxter & Montgomery, 1996; Petronio, 2002). Scholarship has focused on a wide array of topics concerning open communication and avoidance including patient privacy (Petronio & Kovach, 1997), cancer coping and couples (Goldsmith et al., 2009) and family secrets (Vangelisti, 1994). “This widespread scholarly interest is justified because openness and avoidance connect with important individual, relational and social outcomes” (Goldsmith et al., 2009, p. 63). Openness and avoidance entails processes fundamental to the human experience such as privacy regulation, uncertainty management, information seeking, and the expression of feelings.

There are many reasons patients may decide to withhold or disclose information. For example, Kimberly, Serovich, and Greene (1995) found HIV positive patients would use open communication because they desired catharsis. One of the most widely cited reasons individuals withhold information involves an effort to prevent others from forming a negative impression (Goldsmith et al., 2009; Petronio, 2002). This reason is common for people with HIV who worry about the stigma associated with it (Greene & Faulkner, 2002), and family members who worry that outsiders may judge their family (Vangelisti, 1994). Other reasons to avoid communication include concern that the other person would respond appropriately, avoidance of topics that may cause the relationship to deteriorate, or concern about how others will use the information against them (Caughlin & Golish, 2002; Greene & Faulkner, 2002). Finally, some may not disclose information in order to protect others. For instance, research on HIV positive mothers

revealed they did not tell their children about their health because they did not want to worry the child (Siegel & Schrimshaw, 2002).

Individuals may use open communication for a variety of reasons as well. Researchers have found an association between disclosure and relational closeness (Goldsmith et al., 2008). Individuals reveal private information because they trust the other person. Another reason for revealing information is that keeping secrets causes distress. Serovich, and Greene (1995) found that HIV positive individuals often disclosed information about the illness because they wanted catharsis. Self-disclosure correlates with satisfaction in romantic relationships (Dindia, 2000) and can improve mental and physical health (Smyth & Pennebaker, 2001). Open communication can also let others know one needs comforting or tangible support (Goldsmith et al, 2008).

Context plays an important role in the decision to use open communication or to avoid communication about certain topics. For example, Goldsmith, Gumminger, and Bute (2006) found that some heart disease patients did not want to discuss their illness because it would imply the patient was still sick. By not talking about it, the patient could construct a non-ill identity. Context may also play a role for FMS patients. Rodham et al., (2010) found that many participants did not want to discuss their illness for the same reasons. If they looked healthy and acted healthy, then people would believe they are healthy. However, without disclosing the illness, they are unable to acquire specific social support. There are consequences for both openness and avoidance.

In North America, scholarship tends to favor openness over avoidance (Goldsmith et al, 2008). Research overall treats openness as inherently desirable, and avoidance as

inherently problematic (Afifi, Caughlin, & Afifi, 2007). Some research supports this bias. For example, Caughlin and Golish (2002) found that avoiding topics in close relationships generally predicts dissatisfaction. Yet, other theory and research argues that there are times when avoidance may be good for a person or relationship. For example, Baxter and Montgomery's (1996) dialectical approach has revealed that while there is a need to be open and disclose information, there also exists a need to keep some secrets in relationships. Additionally, communication privacy management theory (Petronio, 2002) posits that both openness and avoidance can be useful in relationships, although each has benefits and risks.

Coping and Social Support

Coping mechanisms may also have an effect on how one is able to locate and accept social support. A stressor is an outside force that causes life disruption (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986.). The resulting psychological state that is induced in the individual as a result of the stressor (i.e. FMS) is referred to as stress. Illnesses such as FMS are just one type of stressor, and often individuals have multiple stressors present at any given time. This means that the state of stress is completely unique and depends on the distinctive blend of stressors. Additionally, not all illnesses function to induce stress to the same degree or in the same way, nor are all illnesses considered the same type of stressor (Wolf, 2009). Yet, one individual reaction to a personal stressor, such as FMS, can be seen in the person's ability to cope with the life disruption caused by the disease. Folkman et al. (1986) originally conceptualized coping as a response device that individuals enact to alleviate the negative impact on

one's well-being as a result of distress caused by a stressor. Cognitive appraisal and coping are factors that are assumed to buffer the outcome of stressful situations, like chronic pain. As this body of research has progressed, some researchers have found that interpersonal factors may influence virtually every aspect of the coping process (Eckenrode, 1991; O'Brien & DeLongis, Pomaki, Puterman, & Zwicker, 2009). This includes how one appraises the stressful events, the selection of coping strategies, and the impact of stress on well-being. Similar disruptive situations lead those affected to elicit similar patterns of coping. For example, Stone and Neale (1984) found that people showed moderate levels of within-person consistency when they were coping with the same stressor over time. Additionally, Compas, Forsythe, and Wagner (1988) found that participants showed a consistent pattern of coping when dealing with the same stressor over a period of time. Yet when individual coping is evaluated across different types of stressors, these investigations found low levels of consistency.

Coping theorists have identified three ways of coping with stressors: problem-focused, emotion-focused, and perception-focused (Kahn, Wolfe, Quinn, Snoek, & Rosenthal, 1964; Folkman et al., 1986; Pearlin & Schooler, 1978). Problem-focused coping involves direct actions on the environment or on the self to remove or alter the circumstances perceived as threatening. Emotion-focused coping consists of actions or thoughts to control the undesirable feelings that result from stress. Finally, perception-focused coping involves cognitive attempts to alter the meaning of the difficulties so they are perceived as less threatening. Thoits (1986) suggests that social support may be conceptualized as coping assistance. The researcher asserts that problem-focused coping

and instrumental support can be conceptualized as the same because they both are directed at changing or managing the situation. Additionally, emotion-focused coping and emotional support are also conceptually identical as each try to relieve the negative feelings that usually accompany stress exposure. Finally perception-focused coping and informational support are conceptually the same because both attempt to alter meaningful aspects of stressful situations. Social support, therefore, can be seen as the active participation of relational others in an individual's stress-management efforts.

Stressors may also add to the social constraints surrounding the person affected due to the context in which they occur (O'Brien et al, 2009). Situational consistencies in coping can be categorized into two forms: agentic (task-oriented) and communal (interpersonally-oriented). For example, problem-focused strategies are used more in workplace situations rather than interpersonal situations (Folkman & Lazarus, 1980; Folkman, et al., 1986; Terry, 1994). O'Brien and DeLongis (1996) found that situational factors can be a powerful predictor of the ways in which people cope with a stressor. Their data revealed that the type of situation causing stress accounted for a significant amount of the change in coping responses. Participants were more likely to use problem-focused coping strategies for work-related stressors and emotion- or relationship-focused coping strategies for interpersonal-focused stressors.

Stress and coping affect the ways people communicate and find support. For both men and women with chronic pain, negative spouse responses to their pain were associated with increased pain severity and decreased marital satisfaction, which led in turn to increased depressive symptoms (Cano, Weisberg, & Gallagher, 2000). Further,

women who perceived themselves as having more aversive emotional support experienced more intrusion and avoidance symptoms related to their cancer (Butler. et al., 1999). RA patients with low marital satisfaction escape into fantasy and find blame. RA patients' perception that they were unable to meet the expectations of their spouse predicts greater depressive symptoms (Bediako & Friend, 2004). Conversely, Berg et al., (2008) discovered that daily collaborative coping between men with prostate cancer and their wives is associated with a more positive mood for both men and women. Moreover, negative emotional transmission between husbands and wives was associated with more frequent collaborative coping.

Social Support and Interpersonal Relationships

Social support is broadly defined as making a person believe “he/she is cared for and loved, esteemed and valued and belongs to a network of communication and mutual obligation” (Albrecht & Goldsmith, 2003, p. 264). These types of interactions have a very large impact on an individual's health as well as psychological well-being. Studies show that social support may benefit one's overall health by changing behaviors and easing stress (DiMatteo, 2002; Kaplan, Cassel, & Gore, 1977). Social support is a highly reciprocal process and usually only occurs in intimate relationships such as close friends, family members, or partners (Albrecht & Goldsmith, 2003).

Social support types. Social support processes are strongly linked to both mental and physical health (Cohen, Gottlieb, & Underwood, 2000). While this link has been recognized for some time, some researchers (e.g., Haber, Cohen, Lucas, & Baltes, 2007) argue that limited progress has been made in understanding the more specific

mechanisms that link social support and health. To better understand social support, researchers have described it as a meta-construct which consists of several sub-constructs (Heller & Swindle, 1983; Vaux, Reidel, & Stewart, 1987). Two types often studied together are received social support and perceived social support (Edwards, Rose, Edwards, & Singer, 2008; Helgson & Gottlieb, 2000). Received social support is the actual amount of support an individual receives when encountering a stressor, whereas perceived social support is the person's belief that the support is available if needed (Edwards, et al., 2008). Many studies have focused on both the aspects of perceived and received social support. Researchers have found that received social support can be linked to relational trust, relationship satisfaction, commitment, and perceived understanding (Avtgis, 2003; Cayanus, Martin, & Weber, 2004; Rittenour & Martin, 2008; Weber, Johnson, & Corrigan, 2004).

Yet, studying these two sub-constructs carries additional complications. According to Haber, Cohen, Lucas and Baltes (2007), received support measures ask participants to recall specific examples of behavior rather than a general impression. Therefore, they are thought to be more accurate in the reflecting actual support provided than are other measures. Conversely, perceived support measures may be subject to individual differences in perceptual conclusions and memory processes that may result in a more distinctive perception of supportive events (Lakey & Drew, 1997). Also, Sarason, Sarason and Pierce (1995) found that perceived social support may be influenced by value judgments regarding the relationship in which the supportive events occur.

In addition to perceived and received support types, many scholars discuss other distinct forms of social support: emotional, instrumental (tangible), informational, esteem, and appraisal support (Beehr, 1995; Brock & Lawrence, 2009; Burleson & MacGeorge, 2002; Cohen, Gottlieb & Underwood, 2000; Ostberg & Lennartsson, 2007; Tardy, 1994). According to Burleson and MacGeorge, emotional support is a verbal or non-verbal goal-directed behavior that is aimed at helping an individual cope with emotional distress in order to improve the individual's overall affective state.

Informational support (Terry, 1994) is that which offers to help the individual or provide the person with assistance, information, material aid, advice or guidance. Tangible support includes taking on responsibilities for someone else, so they can deal with the problem. Esteem support is shown by expressing confidence or encouragement (Brock & Lawrence, 2009).

The number of dimensions and the labels used for them vary, but two categories tend to pervade the support literature, emotional and instrumental support (Semmer, et al., 2008). Yet, the distinction between types of support is problematic because the types of support are highly correlated, especially when the support is coming from the same person (Fenlason & Beehr 1994; Willis & Shinar, 2000). To counteract this difficulty, researchers often combine the types of social support into one global measure (Beehr, 1995; Cutrona & Russell, 1990; Schonfeld, 2001). However, using this procedure only works if one assumes that different types of support do not have dissimilar consequences. Such assumptions cause additional problems in research because the ability to measure the specific contribution to health and well-being is lost in a general measure.

Scholars who argue for specific implications of different support types usually do so to argue that one component is most crucial to situational requirements. Many see emotional support as the most important type (Berkman, 1995; House, Landis, & Umberson, 1988; Thoits, 1995). However, other investigators (e.g., Schwarzer & Leppin, 1991) found instrumental support to be the strongest predictor of physical health. Complicating these matters further, Ostberg and Lennartsson (2007) found “economic support” as the most predictive of health, followed by “companionship” and the option to talk about personal issues. One of the primary reasons for such discrepancies in social support type research is the extent to which the investigator takes into account situational variances and their effects on how individuals seek and find support. Many scholars have argued for the necessity of considering situational characteristics when examining the supportive action (Cohen & Wills, 1985; Cutrona & Russell, 1990; Cutrona & Suhr, 1994; Semmer et al., 2008). It is reasonable, for instance, to assume that instrumental support is particularly appropriate in circumstances that are controllable, whereas emotionally comforting behavior would be needed more if nothing can be done about the problem. Regardless of these nuances, types of social support are highly correlated. High association between the different types may stem from the fact that people who are helpful have a good understanding of what is needed in each instance (Semmer, 2008) and may be able to smoothly match the type of support they provide to the situational characteristics. Further, Barling, MacEwen, and Pratt (1988) argue that each type of support may actually carry multiple meanings. In their research, participants responded to a hypothetical

vignette and indicated that instrumental support was perceived as being emotional in nature as well.

Enacted social support. Conversations in which individuals talk about problems—from hassles of daily life to the major life events that bring stressful challenges, threats, or losses—can be conceptualized as social support (Fisher, 2010; Goldsmith, 2004). Enacted social support can be defined as what people say and do for each other and how this behavior can improve well-being (Fisher, 2010), yet across disciplines, researchers interested in social support rarely examine communicative behavior. The interactions in which individuals communicate different types of social support are an essential feature of the complex social support construct (Goldsmith, 2004), and unfortunately the process of how it is communicated is the least studied element. Enacted social support is different from other conceptualizations of social support that focus on the quantity or existence of relationships and perceived support, or the perception of support that is or would be available when needed (Fisher, 2010). For example, self-report surveys tend to focus on scales to determine patients' perceptions of available support (Bloom & Kessler, 1994; Smarr et al., 1997; Schoofs et al., 2004). However, how patients communicatively enact support does not receive as much attention. In research that does focus on the communicative behavior of social support, three types of support are typically discussed: emotional, informational, or instrumental, as reviewed previously.

Helpful or unhelpful enacted support. Researchers also focus on ways in which supportive communication is helpful or unhelpful. According to Goldsmith (2004),

some pieces of advice may be wiser than others, or some emotional support attempts may come across as heartfelt, whereas others may seem superficial. There is a large body of scholarship that identifies helpful and unhelpful behaviors reported by individuals with a wide variety of conditions and stresses (Dunkel-Schetter, 1984; Goldsmith, 1992; Ingram, Betz, Mindes, Schmitt, & Smith, 2001). By finding types of social support communication as helpful or unhelpful, scholars are able to understand how the support functions as adaptive or maladaptive. For example, Dunkel-Schetter (1984) found that cancer patients perceive emotional support as more helpful than informational or instrumental, whereas Rodham, Rance, and Blake (2010) found that instrumental support from spousal caregivers was extremely helpful to FMS patients.

Context. It is important to understand that enacted social support is a communication process. The actions that make up enacted social support have meaning for the participants, observers, and researchers. Further, the effects of enacted social support do not come about mechanistically or causally, but rather through the participants' interpretations and evaluations (Goldsmith, 2004). These meanings are based not only in the individuals but also in the context. According to Fisher (2010), context is a critical, multi-dimensional, and significant factor in the interaction experience. Context may be based in social, relational, physical, and temporal aspects and are critical to understanding supportive communication and its outcomes (Albrecht & Goldsmith, 2003). Therefore, examining context is necessary for understanding how and why we see enacted support behaviors as helpful or unhelpful. Studying enacted support within context is necessary as it will help to answer questions about which actions are

considered meaningful and purposeful (Goldsmith, 2004). To study enacted support within context, research needs to begin by focusing on eliciting stories and details about who, what, when, where, and how the support was enacted. This cannot be performed through a self-report survey methodology alone, but must be accomplished through qualitative means. A retrospective interview technique (RIT) method may be useful for understanding the contexts of supportive communication and how it was enacted because this method can locate key contextual factors at every turning point. Additionally, through the use of a mixed method sequential exploratory approach, the qualitative RIT data informs the second stage quantitative data allowing the researcher to select scales more appropriate to the context. One scale that may be particularly useful for this study is the Medical Outcomes Study-Social Support Survey (Sherbourne & Stewart, 1991). This survey was designed to focus on patients with acute or chronic illnesses and with a wide array of social support needs.

Health effects. Social support can also help people through illness and medical problems. Research revealed the positive effects of supportive interaction and social relationships on health and well-being for individuals (Krause, Lang, & Yatomi, 1989; Lackner et al, 1993). Supportive interaction improves resistance to and recovery from disease (Cohen, 2004; Seeman & Crimmins, 2001; Lett et al., 2007; Spiegel & Kimerling, 2001), reduces mortality (Berkman, 1995; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Lyyra & Heikkinen, 2005), and has a very large impact on individuals with heart failure (Bennett, et al., 2001). Participants who were surveyed said social support not only helped their quality of life but helped their

health as well. Rankin and Monahan (1991) found similar patterns between couples. They studied the effects of social support one to three months after a cardiac surgery. Good social support helped with the burden of care giving. Furthermore, social isolation is associated with higher age-standardized prevalence of hypertension, diabetes mellitus, current smoking and higher daily alcohol intake, as well as lower mean exercise levels (Achat, Kawachi, Levine, Berkley, Coakley, & Colditz, 1998).

Chapter Summary

This chapter examined the literature associated with stigma, coping and social support with a framework of chronic illnesses and specifically FMS. Particularly, this chapter focused on the how diagnosis of a stigmatizing illness affects a patient's abilities to find social support and to cope. Traditionally, research has shown that social support has a great impact both psychologically and physiologically. Individuals who receive appropriate support from their relationship partners are more likely to have reduced stress and are more likely to find useful roads to recovery. This chapter discussed not only the effects of social support, but also the types of support previous research revealed to be helpful. Researchers found that social support requires open communication between interactants and must be understood within the context in which it occurs. Additionally, the literature revealed that not all social support is perceived as helpful, so it is imperative to understand the differences between the two and the effects of unhelpful support on communication.

CHAPTER THREE

This chapter discusses the methodology used to answer the research questions presented in Chapter 1. To answer these questions, this dissertation has used a sequential exploratory mixed methods design, which combines qualitative and quantitative data. The qualitative data was derived from a modified retrospective interview technique (RIT) (Huston, et al., 1981). A RIT method was used to collect turning point data and to conduct in-depth interviews with FMS patients. A transcendental phenomenological method was used to develop a textural description and a structural description of the participants' experiences. After the qualitative data were gathered and analyzed, a quantitative questionnaire stemming from the findings of the qualitative analysis was designed to explore two deductive research questions.

This chapter is divided into three major parts. The first section discusses the mixed method. Part two includes a description of the qualitative instruments, data collection procedures, recruiting source for participants and a description of the data analysis techniques that were utilized in this section of the study. Finally, part three of this chapter includes a discussion of the research design, description of the quantitative instrument, data collection procedures, population and sampling, validity and reliability, and data analysis techniques.

Mixed Methods Approach

A mixed methods approach was best suited for this study primarily because combining and integrating qualitative and quantitative approaches to research, sharpened the understanding of the phenomenon and the research findings (Gay & Airasian, 2000; Tashakkori & Teddlie, 2003). Creswell and Plano Clark (2007) also state that a mixed methods approach involves a use of both approaches so that the overall strength of the study is greater than either qualitative or quantitative alone.

Historically, mixed methods research is relatively new compared to quantitative and qualitative methods. According to Tashakkori and Teddlie (2003), there was a traditional period in mixed methods research from 1900-1950. During this time, there was a substantial volume of important mixed methods research due to little methodological controversy. This was caused by less orthodoxy in methodology during this time. While there was some discussion of the merits of qualitative and quantitative approaches, there was relatively little debate between the two that would later come. While for many years those using a mixed methods approach had no need to bring attention to their distinct orientation, paradigmatic debates led mixed methodologists to explain why this methodology is not only an appropriate approach to research design but may also lead to the ability to answer questions quantitative or qualitative methods individually cannot.

While there are many notable advantages to a mixed method study design, there are also disadvantages (Creswell, 2009). Some of these disadvantages include the need for extensive data collection, a time-intensive nature of analysis, and that the researcher must be familiar with both quantitative and qualitative forms of research. Tashakkori and

Teddlie (2003) find that other disadvantages accompany a mixed methods design: it may be difficult to sell to reviewers of journals, it may be higher in cost, it may need additional background information and it may require researchers to work in multiple teams. Yet, the advantage of gaining a deeper understanding of the phenomenon of interest far outweighs these disadvantages. Collecting and analyzing both numbers and words in a single study allows the research to mirror the way people tend to understand the world around them (Hanson, Creswell, Plano Clark, Petska, & Creswell, 2005). According to Creswell and Plano Clark (2011) by combining both inductive and deductive thinking, the research is able to base knowledge claims on pragmatic grounds. For these reasons, this study will use a sequential exploratory design.

Sequential Exploratory Design. The sequential exploratory mixed methods design consists of two distinct phases: qualitative followed by quantitative (Creswell et al., 2003). In this design, the researcher first collected and analyzed the qualitative data. The quantitative data collection occurred second in the sequence and helped build on the results of the qualitative phase. Creswell (2009) states that unlike the sequential explanatory approach, which is used for explaining and interpreting relationships, the primary focus is to explore the phenomenon. Morgan (1998) also suggests that this design is appropriate to use when testing elements of an emergent theory that results from the qualitative phase. Finally, according to Creswell (2009) this mixed methods strategy is often discussed as a procedure of choice when a researcher needs to develop an instrument because existing instruments are inadequate or not available. This is extremely helpful for the topic of communication and FMS patients as no previous instruments have

been designed that focus on this topic. Hence, the results of the qualitative study allowed informed selection of measures for the quantitative study. Previous research on FMS and communication primarily uses a qualitative methodological approach, and therefore a sequential mixed method will be able to further the knowledge of this phenomenon beyond what has previously been done.

The advantages of this approach according to Creswell (2009) are that it is easy to implement and straightforward to describe and report. It is useful for a researcher who wants to explore a phenomenon but also wants to expand on the qualitative findings. The disadvantages as described by Creswell are a substantial length of time to collect data and that the researcher must make some key decisions about which findings from the initial qualitative phase will be focused on during the quantitative phase.

Phase I: Qualitative Research Design

The qualitative phase of the research design set out to explore the ways in which women with FMS seek social support and what barriers they encounter when doing so. Specifically, the following research questions were posed:

RQ1: What turning points characterize women's experiences with FMS?

RQ2: What turning points characterize women's experience in finding barriers to and the need for support with a relational other?

RQ3: How are relational turning points associated with illness turning points?

This phase of the study focused on capturing the experiences participants with FMS have in finding social support. Because this phase focused on participants' lived experiences, the researcher took a naturalistic approach to the research and illuminated these

experiences by using qualitative research data collection and analysis methods. This was performed through a modified retrospective interview technique (RIT) (Huston, et al., 1981). RIT is a method of interviewing participants that asks them to focus on past experiences and further probes these experiences for data. A RIT method was used to collect turning point data and to conduct in-depth interviews with FMS patients. A phenomenological technique was also used to classify themes found in the data.

Methodological Paradigm. A naturalistic paradigm was appropriate for this phase. Previous chapters have discussed the difficulty women with FMS have in being diagnosed, as well as the psychological and relational ramifications. There are many facets to this problem, but Crooks (2007) states that one possible facet is that male values and characteristics are considered normative within the health care system, which reinforces the patriarchal nature of the hierarchical health care system. While the interaction between doctors and patients are not the focus of this study, the relationship is still significant as it can greatly affect the patient both physically and mentally. This is especially true if the doctor misdiagnoses FMS for a psychosomatic condition. Gannon (1998) argues that in the context of chronic illness, traditionally a woman's experience with pain is more likely than a man's to be classified as being psychosomatic, or even hysteric, in nature. It is also more likely to be either ignored or mistreated by mental health professionals. Researchers found that at the beginning of the 19th century the diagnosis of hysteria was part of the expectation of the feminine gender and the woman should be seen as delicate and weak (Werner, Isaksen, & Malterud, 2004).

Not only are women misrepresented in medicine, but they are also misrepresented or even dismissed in research. Riger (1992) states that social science has neglected and distorted the study of women in favor of men. If this study were to solely focus on quantitative research, it would leave the interpretation of women's experiences to the results of standardized scales rather than on the lived experiences shared by the women participants. Therefore, this study will begin with qualitative methods and the use of turning point analysis, which will provide a unique framework for studying how women with FMS find support.

Morawski (1997) states that qualitative research methods provide an excellent framework when attempting to understand experiences of a person suffering with an invisible or chronic illness. This is because these methods allow the researcher to identify themes and actions through the participants own words and experiences. Also, RIT gives participants authority and voice in their subjective inferences regarding their lived experiences rather than researchers using objectively based inferences on behalf of the participants (Bolton, 1961; Siegert & Stamp, 1994). Lincoln and Guba (1985) also discuss how a naturalistic paradigm offers rich contextual relevance which is unmatched by any other paradigm. According to Golafshani (2003), qualitative research uses a naturalistic approach because qualitative methods focus on understanding the phenomena within its context. Creswell (2007) states that this is different from quantitative methods, which are also called the positivistic approach, in that quantitative methods attempt to make predictions based on previous research, posit hypotheses and generate generalizable findings. The problem with solely using a quantitative methodology for the FMS

population is that because they are marginalized, they have a limited voice in previous quantitative research, which causes difficulty when posing hypotheses.

For these reasons, a qualitative naturalistic inquiry was used during this phase in order to explore this experience. To conduct the study, the researcher followed the guidelines outlined by Lincoln and Guba (1985). This includes a statement of a problem that may change throughout the study, an understanding that theory emerges from the inquiry, and a statement of procedures used. This also includes finding data where the researcher can maximize the scope and range of information obtained; the use of the human instrument that will become more refined in the process. In order to refine the human instrument, measures should be taken such as bracketing biases, using thick description, and performing member checks. Lastly, Lincoln and Guba (1985) discuss performing data analysis procedures that are open-ended and inductive. In order to analyze data that concurs with Lincoln and Guba's outlines, this research uses a phenomenological analysis technique. A phenomenological technique focused on the descriptions of the experiences of the participants. Because this methodology was focused less on the interpretations of the researcher, Moustakas and Husserl (1931) state that the researcher should bracket, or set aside, their experiences as much as possible in order to have a fresh perspective when viewing the data. While Moustakas suggests bracketing at the end of the data analysis, Creswell (2007) recommends bracketing before when discussing the role of the researcher. In line with what Creswell asserts, I bracketed my experiences with FMS before the data analysis.

Validity: Role of the Researcher. Qualitative research is interpretive in nature, which means the researcher must make sense of the meanings found within the data. Yet one major criticism of qualitative methods is the use of the researcher's own experience in the research process (Keyton, 2001). To do this, researchers must discuss their preconceptions or bias to help the reader understand how the interpretations and meanings have been placed on the findings (Creswell, 2007). Husserl (1931) first discussed bracketing in phenomenological methodology and suggested researchers suspend all judgments about what is real until they are founded in a more certain basis. Bracketing allows the researcher to separate his or her perspective during the data collection. This is done to help the reader understand both the emic, or participant centered understanding, and the etic, or researcher centered understanding of the phenomenon (Creswell, 2007). To best perform this research, I must bracket my own experiences as a person with chronic pain syndrome and analyze how these experiences may have biased my understanding of the topic. While Husserl and Moustakas (1994) assert that personal experience should be removed from the research, Lincoln and Guba (1985) argue that personal experience can help develop the audience's understanding of the phenomenon.

Validity: Bracketing. The researcher has past experience with chronic pain, and the standpoint must be discussed as it may lead to biases when conducting this study. A detailed explanation of the experience can be found in Appendix A. The first bias the researcher holds is the difficulty to self-disclose about a stigmatized illness. Through personal experience, the researcher found it difficult to tell others about the invisible

illness. This was caused by uncertainty as to how others will react to the news and stems from a fear of what others will think. This bias motivates the researcher to better understand how communication affects social support seeking behaviors and the subsequent effects on coping. In order to perform a naturalistic inquiry through a phenomenological technique, the researcher must be sure these biases do not affect the interview or data analysis and must be cognizant of not leading the participants in the interview process. To better help mitigate this barrier, rich descriptions need to be used regarding the illness and social support and a member check was performed to mitigate bias.

Another bias the researcher has stems from personal experience, and the research on FMS and disclosure is the effects the diagnostic process has on later disclosure and social support. Researchers found that FMS patients have a difficult diagnostic process (Choy et al, 2005), which was also present in the researcher's experience. Researchers have also established the connection between feelings of legitimacy and the diagnostic process. Through personal experience, the researcher experienced feelings of illegitimacy which affected the ability to find social support. This belief stemmed from the lack of a formal diagnosis. If the medical community was unwilling to diagnose a problem, the researcher believed social networks would follow suit. This bias was diminished through constant evaluation of assumptions throughout the data collection and analysis phases. The researcher was mindful to use no leading questions in the interview process and through the data analysis focused on what was emerging from the data rather than allowing any bias to affect the analysis. The researcher also used methods of

triangulation, such as member checking and thick description to further reduce this bias. Thick descriptions were also used when explaining all findings to help the audience understand the theme or finding through the participants' own words.

Another researcher bias concerns altered identity. This bias affected the research design through participant selection. Because the researcher experienced changes in identity formation while waiting for a formal diagnosis, participants who have not been diagnosed with FMS or who have very recently been diagnosed with FMS may also be affected by this phenomenon. Some researchers have focused on the impact illness has on a person's identity (Asbring, 2000; Henriksson, 1995; Karp, 1994; Kundrat & Nussbaum, 2003). Limiting the participants to women who had been diagnosed over a year previously generated a better sample as the women had time to identify with the diagnosis. To mitigate this bias, the researcher focused on identity research concerning diagnoses and invisible illness and found that personal conclusions were reflected in the literature, validating the decision to use a sample that had been diagnosed over a year. Asbring (2000) found that FMS caused a major disruption in the women's biography, which had profound consequences on their identities. Henriksson (1995) discusses the activity loss that many FMS patients face, such as a reduced social life and the inability to work. This research also found that FMS patients were required to make adjustments to their lives to accommodate the illness that lead to a loss of a previous identity. Karp (1994) found that a diagnosis of mental illness also had an impact on patients' identity. The patients in the study underwent new identity formation after they were diagnosed

through reconstructing their identity. Finally, Asbring (2000) concluded that FMS patients reconstruct their identity over time.

Validity: Intensive data collection. Another way to add validity in this study was through rich, thick descriptions. Intensive interviews enable the researcher to collect “rich” data, or data that is highly detailed and varied enough to reveal the full picture of the phenomenon (Maxwell, 2005). Through the use of RIT and the turning point interview guide, the researcher was able to ask open-ended questions which allowed the participants to elaborate on their experience as they saw fit. Also, the turning point graphs helped the participants to see a full picture of their experience before the interview questions took place. This helped the participants elaborate further by allowing them to be grounded in their experiences. If the participants were less descriptive for an interview probe, these techniques also allowed the researcher to ask follow-up questions.

The literature on social support regarding health contexts is clear: social support improves patients’ health (Achat, et al., 1998; Cornman et al., 2003). For example, literature shows that people who have FMS and have support are less likely to be depressed and use fewer pain killers than those who have little support. These individuals are also more likely to participate in healthy behaviors such as light exercise to help the pain (Ursal & Lu, 2011). I sought to understand not only how FMS patients seek support but also what effect their experience with the disease has on their ability to find social support.

Phase I: Instrumentation and Data Collection

Participants. In qualitative research, sample size is not predetermined as in quantitative research methods. Rather, qualitative researchers collect data to a point where “we notice that our concepts and propositions are not disconfirmed as we continue to add new data” (Lindlof & Taylor, 2002, p. 129). Data collection was conducted with this in mind. The sample consisted of women who are over the age of 18 and have been diagnosed with FMS for over a year. Participants must have been over the age of 18 to participate following International Review Board (IRB) protocol. The participants must also have been diagnosed with FMS for at least a year, as explained previously. While there are many disorders and diseases that cause chronic pain, this research is focused on the experiences of individuals with FMS. This follows Moustakas’ (1994) guidelines for research in that by limiting the disease to FMS, there will be consistency in the data. Participants also needed to have been diagnosed for a year because the time frame from diagnosis is determined in conjunction with the use of RIT. RIT requires participants’ retrospective reflections and descriptions of an experienced phenomenon. Participants must be able to reflect on the process of being diagnosed and coping with that diagnosis. Additionally, the participants without the diagnosis may be less interested in seeking support from their interpersonal relationships and more interested in discovering why they are in pain. Another reason is that once the participant has been diagnosed, their identity can be shaped by this diagnosis (Eccleson, Williams, & Rodgers, 1998). Limiting the sample to those who have been diagnosed over a year also gives the participant time to identify with the diagnosis. Asbring (2000) found that a diagnosis of FMS had a profound impact on their identity. In time, the participants started to adopt a new identity

after they were diagnosed. Asbring found that the timing of diagnosis affected the participants' ability to adopt a new identity, therefore it was imperative that I limit the participants to those who have been diagnosed at least a year before the time of the interview. I felt that participants could process and reflect on their FMS experience a year following diagnosis.

Participant recruitment. A purposive sample of participants was recruited in three ways. The first is through outpatient rheumatology, neurology, and physical therapy clinics in the Washington D.C. area that were run by medical and nursing staff. Two clinics agreed to participate in recruiting. The second way participants were recruited was through the National Fibromyalgia Association Registered support groups in Virginia and Maryland. Twenty-three support group leaders were contacted to request permission to recruit from their members. Four support group leaders agreed to participate in the study and forwarded the call for participants to their members. The criteria for the study was that an experienced clinician has diagnosed FMS more than a year prior and the participant is over the age of 18. They must also have been able to communicate effectively in English. Because too few participants were recruited through these methods, a snowball sample was also used. The author provided information to professional contacts who then reached out to potential participants and gave them information about the study.

Sample Description Phase 1. Seven women participated in this phase of the study. Below is a table of each woman's demographic information. The name for each participant was changed to protect her anonymity.

Table 3.1: Sample Demographics

| Name | Ethnicity | Age | Date of diagnosis | Single or Married | Work Status | Number of children | Ages of Children |
|--------------|-----------|-----|-------------------|-------------------|--------------|--------------------|------------------|
| 1. Kate | Asian | 49 | 2010 | Married | Part time | 2 | 14 & 18 |
| 2. Moira | Caucasian | 32 | 2011 | Married | Doesn't work | 2 | 2 & 5 |
| 3. Jane | Caucasian | 43 | 2007 | Married | Part time | 3 | 5, 9, & 11 |
| 4. Angela | Hispanic | 47 | 2010 | Married | Full time | 2 | 9 & 18 |
| 5. Charlotte | Caucasian | 68 | 2009 | Married | Part time | 1 | 27 |
| 6. Brenda | Caucasian | 30 | 2011 | Married | Doesn't work | 2 | 3 & 6 |
| 7. Sally | Caucasian | 62 | 2009 | Married | Doesn't work | 1 | 31 |

Instrumentation and Data Collection Phase 1. As this phase of the study was primarily concerned with the participants' lived experience of the phenomenon of support seeking, it was essential to employ methods of data collection sympathetic to an underlying naturalistic inquiry using a phenomenological technique. As stated previously, a modified RIT was used and in-depth interviews focused on how women with FMS experience the disease and how they communicate social support needs at the onset of symptoms, across the course of the disease, and up to the present. This made it possible to understand the changing nature of the FMS experience and the ways participants found support throughout the experience, as well as to obtain baseline data.

Preparation for the interviews. The interviews focused on discussing the participants' experience with FMS and social support in their lives. This was accomplished through a modified RIT method. Once participants agreed to join the study, they each received a study packet. The packet contained a cover letter regarding

preparation for the interview, an IRB-approved informed consent document, a general background information sheet, and a RIT graph (see Appendix B for the sample study packet). If due to a home residence 60 miles or more outside of the campus area, participants were not be able to meet face to face for an interview, a self-addressed, stamped return envelope was included with the packet. Those participants were instructed to return all necessary documents (completed and signed) prior to scheduling a phone interview. Once the materials were received by mail, the participants were contacted to schedule a phone interview. Participants who were able to arrange face-to-face interviews were instructed to hold the packet until we met. Participants who met with the researcher in person were contacted in order to schedule interviews within 72 hours after mailing the study packet. As previously stated, the participants received the graph prior to the interview, which gave them an opportunity to reflect on their FMS-related experience and their social support behaviors.

Each participant was asked to think of their experience with FMS as well as a primary relational partner with whom they have discussed this experience. With this in mind, they were then asked to plot two trajectories on the RIT graph. The first trajectory focused on their symptom experience, with major events noted as turning points. The second trajectory focused on turning points in communication for social support. For each trajectory, time or course of the disease was represented on the horizontal axis as turning point analysis focuses on change. The symptom experience was represented on the vertical axis for the first trajectory and social support communication was represented on the vertical axis for the second trajectory. The upper levels of the vertical axis

represented high symptom experience (extreme pain or fatigue) for the first trajectory and high social support communication (high use of discussing the disease with the primary relational partner) for the second trajectory. The lower levels of the vertical axis represented low symptom experience (few debilitating symptoms) for the first trajectory and low social support communication (low use of discussing the disease with the primary relational partner) for the second trajectory. The use of two plot lines permits a better understanding of how the FMS experience relates to finding social support.

Instructions for how to complete the graph appeared on the graph itself. They were as follows:

Please know that there are no right or wrong answers. Everyone who completes this graph has a unique representation of their experiences with fibromyalgia.

Please use this graph to plot out turning points you have experienced as they relate to fibromyalgia. These turning points are moments when you recall changes in your overall experience, and in the ways you communicated about your experience. This graph is a chance for you to reflect on your experiences and take some time to recall them. We will use this graph to guide us during the interview.

You will plot two lines:

1. one line will be your perspective of changes in your illness symptoms
2. the second line will your perspective of times when you looked for support from your primary relational partner

Please begin with the first line, or your experience with fibromyalgia symptoms. Recall the period before you were diagnosed and plot your symptom experience at that time, above the label, "Pre-diagnosis." "Low symptom experience" means you were experiencing very few symptoms and "High symptom experience" means you were experiencing extremely debilitating symptoms. Place a dot on the graph to represent this.

Now make any dots on the graph when you felt your symptom experience changed and became more or less debilitating. You may recall changes due to a specific event (e.g. a new medication relieved symptoms) or it may not be in reference to a specific event (e.g. you just recall symptom changes for some reason). You may also recall turning points that didn't specifically relate to fibromyalgia but clearly affected the symptoms (e.g. a new job; death of a family

member; etc.). You may find these important to your experience, so please feel free to plot them as well. Do this up until the present day. Once you reach the end of the graph, please rate your present symptoms above the label “Present Day.” Finally, connect the dots that you plotted with a line. Label it “Line #1.”

Now I’d like you to plot your experience communicating with primary relational partner for support. This could be anyone from a spouse, to child, to friend. Above the graph, please write down who this partner is. Recall the period before you were diagnosed and plot your use of supportive communication at that time, above the label, “Pre-diagnosis.” “Low supportive communication” means you did not seek much support from the relational partner, “High supportive communication” means you sought a high amount of support from this person. Continue with this in the same manner you did for the symptom experience, noting any changes in supportive communication throughout your experience with the disease. Once you reach the end of the graph, please rate the present amount of communication you seek above the label “Present day.” Connect the dots that you plotted with a line. Label it “Line #2.”

Retrospective interviews. The second procedure of the modified RIT methodology was to carry out an in-depth interview with each participant. A semi-structured interview was used to foster a more conversational tone and to allow talk to flow freely and actively between the interviewer and the participant. Throughout the interview, I followed an interview protocol that outlines the three levels of interview questions according to Ulin, Robinson, and Tolley (2005), which include main questions, follow-ups and probes. During the interview, I discussed each turning point with the participant. Discussion of the first turning point line, which centered on symptom experiences, focused on what effects the symptoms and the disease had on the participant and their relationships (see Appendix C for the complete interview protocol). Key questions for this line included: (a) “How did you cope with this turning point?” (b) “What changed in your life as a result of this turning point?” (c) “Why do you think this turning point stands out?” (d) “How would you describe your communication during this

turning point?” I also discussed each turning point in the second turning point line with the participant. This line concentrates on how the participant sought support from the primary relational partner. Key questions for this line include: (a) “How would you describe your communication at the time of this turning point?” (b) “How did you seek support from your primary relational partner?” (c) “Looking back, what kinds of support did you need from your relational partner during this turning point?” (d) “Why did you seek support?” (e) How was the support you received helpful/unhelpful?”

Phase 1: Data Analysis

All of the participant interviews (face to face and phone) were audio-recorded and transcribed into written transcripts by the primary researcher. The transcripts and audio recordings are protected via password on computers and kept in files that were only accessible by the researcher.

A transcendental phenomenological study describes the participants’ meanings of a lived experience for a particular concept or phenomenon (Creswell, 2007).

Phenomenology is a method where the “primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanations” (Spiegelberg, 1979, p. 3). Overall, phenomenology wants to reduce individual experiences with a phenomenon to a description of its universal essence (Creswell, 2007). In a transcendental phenomenology, “the researcher collects data from persons who have experienced the phenomenon and then analyzes the data by reducing the information into significant statements or quotes and combines these statements into themes” (Creswell, 2007, p.60). In qualitative research, data analysis is where the

researcher, “concentrates on the instance, trying to pull it apart and put it back together again more meaningfully—analysis and synthesis in direct interpretation” (Stake, 1995, p. 75). To facilitate the data analysis process, the interview data were analyzed according to Moustakas’ (1994) guidelines. These guidelines were used because they fit an inductive method. Lincoln and Guba (1985) characterize naturalistic inquiry as a primarily inductive method. They state that an inductive data analysis process is more likely to identify the multiple realities to be found in the data.

Moustakas (1994) discusses a three-step method of analysis. The first step of the analysis is called horizontalization. In this step, the researcher reads through all of the data and pulls out “significant statements” or sentences that provide an understanding of how the participants experienced the phenomenon. Once the significant statements have been found, the researcher can start the second step and develop themes, or “clusters of meaning” (Moustakas, 1994). These clusters or themes should then be linked to the researcher’s experience or to the findings in the literature. These significant statements and themes should then be used to write a description of what the participants experienced, which is called a textural description. The statements are also used to write a description of the context or setting that affected how the participants experienced the phenomenon. Moustakas calls this step the structural description. After themes have been identified, the researcher needs to identify the core essence of the phenomenon as experienced by the participants and write a composite description of the essence or underlying structure of the phenomenon (Moustakas, 1994). Finally, the researcher will develop a textural description of the experiences as well as a structural description of the

participants' experiences. Creswell, (2007) classifies textural descriptions as what the participant experienced and structural descriptions as how they experienced it in terms of the context or situation.

Rather than using the positivistic methods of validity and reliability, qualitative research uses verification procedures to show believability and dependability (Creswell, 2007) as well as trustworthiness (Golafshani, 2003). Therefore, this research used two methods to convey believability, trustworthiness and dependability: using thick descriptions and member checking. Creswell (2007) states that thick description constitutes giving thick, detailed quotes and descriptions from the participants. This allows the readers to see transparency in the study and to come to their own conclusions along with the researcher. Thick descriptions were used throughout the findings section to convey believability. Secondly, this research engaged in member checks to help show the readers that members of the population that is of interest validated the findings (Creswell, 2007). For this study, after the themes were established, a sample of participants were asked to validate the accuracy of the themes. Two of the seven interview participants were contacted and asked to provide insight as to whether the themes were accurate representations of their experience with the phenomena. Those who participated in the member check, reported that their experiences were indeed appropriately represented.

Phase II: Quantitative Research Design

The quantitative phase of this study focused on measuring satisfaction with communication about FMS with a relational partner. From the analysis of the qualitative data (see Chapter 4), several additional research questions emerged:

RQ4: How well do communication competence, perceived communication competence of partner, and relational satisfaction predict perceptions of social support?

RQ5: How well do communication competence, perceived communication competence of partner, relational satisfaction and perception of social support predict perceptions of coping with FMS?

Participants. Participants in this study were recruited through the National Fibromyalgia Association, The American Fibromyalgia Syndrome Association, and the Facebook groups Fibromyalgia Awareness, Fibro Mommies, and ButYouDon'tLookSick and CountingMySpoons. Criteria for the study are that an experienced clinician has diagnosed FMS more than a year prior and the participant is over the age of 18. They must be able to communicate effectively in English. Participants must also be married and able to discuss their illness with their spouse. The marriage criterion was used in order to measure the communication with a steady relational partner. There were not enough participants through this recruiting method, so a snowball sample was used. They were recruited through the researcher's professional social network. The author provided information to professional contacts who then reached out to potential participants and gave them information about the study.

The rationale for the first criterion of being diagnosed by an experienced clinician more than a year prior to the study is to include participants who had at least a year's experience navigating communication with and about the illness. Participants who have been diagnosed prior to a year may not have sufficient experience to answer the questions in the instrument. The rationale for the second criterion is that they must be able to communicate effectively in English. This survey was distributed in English, and a participant who could not precisely understand what the questions were asking may skew the data received. The rationale for the final criterion, communication with their spouse at least monthly, was placed on this sample as the questions in the instrument focus on the satisfaction of communication with one person in their life. These questions could not be answered if they do not discuss their illness with their spouse at least once a month. The sub-criterion of a month was established to form a baseline for the data.

Phase II: Instrumentation and Data Collection

Identification of the dependent and independent variables developed through the themes that emerged from the qualitative data analysis. Reliability coefficients given here for scales are from these data. The questionnaire (Appendix D) contains seven demographic questions, two severity of illness questions, two needs-based questions, one coping question, a single-item measure of relational satisfaction,¹⁰ Likert-style questions about the participants' communication competence through the short-form Interpersonal Communication Competence Scale (ICCS, Cronbach's $\alpha = 0.75$), 20 Likert-style questions on the perceived communication competence of a relational other through the Perceived Communication Competence scale ($\alpha = 0.95$) and 19 Likert-style questions on

the perceived social support through the MOS social support survey (MOS-SS, $\alpha = 0.963$). The questionnaire was programmed into Survey Monkey© and was distributed in the manner outlined previously.

Interpersonal communication competence scale. Rubin and Martin (1994) developed the ICCS, which focuses on ten dimensions of communication competence: self-disclosure, empathy, social relaxation, assertiveness, interaction management, alter centrism, expressiveness, supportiveness, immediacy, and environment control. These items were chosen from existing scales and previous research on communication competence. The original scale was given to 477 students in a college setting. Forty eight percent of the respondents were male, and 52% were female. The original 60-item ICC scale had a coefficient alpha of .77, and alphas for the ten subscales were also computed. The items with the lowest item-total correlations from each of the ten subscales were removed and the overall alpha for the 30-item scale was .86. The scale was modified one final time to reduce the scale to a 10-item questionnaire by keeping the item with the highest item-total correlation from each group. This provided a coefficient alpha for the short-form scale of .63. The short form scale will be used in this questionnaire in order to provide data for the communication competence of self as the independent variable.

Medical outcomes survey- social support. The MOS social support survey (MOS-SS) was developed by Sherbourne and Stewart (1991) and the 19-items cover four domains of social support: emotional/informational support, tangible or instrumental support, positive social interaction, and affection. The MOS-SS was developed from previous instruments, which according to McDowell (2006) has shown to be

psychometrically sound and considered universally applicable. Later, other studies started to modify the MOS-SS in order to reduce respondent burden (Clough-Gorr, 2007; Gantz et al, 2003; Moser et al, 2012). The MOS-SS has four subscales, and each subscale covers a different domain: tangible support, emotional/informational support, affectionate support, and positive social interaction. When building the scale, Sherbourne and Steward found the emotional and informational support subscales to have a high correlation in the confirmatory factor analysis which led to the combination of the subscales. As the MOS-SS was originally based on the Medical Outcomes Study, the researchers included a number of health and well-being measures. This makes the MOS-SS extremely suitable to use in this study. Additionally, the qualitative data revealed an abundance of discussion regarding tangible support and very little discussion on emotional support, making this study well-suited to modified MOS-SS.

Perceived communication competence. Canary and Spitzberg (1987) developed a scale to measure the perceptions of communication competence of an outside source. In the original research, Canary and Spitzberg focused on the appropriateness and effectiveness of communication during a conflict. They asked 361 participants to listen to a conflict script and evaluate the communication competence of the main character or communicator. After a factor analysis, three factors emerged: effectiveness, specific appropriateness, and general appropriateness. The coefficient alphas for each factor are as follows: .93 for effectiveness, .85 for specific appropriateness and .82 for general appropriateness. This scale was used in this study to discover the perceptions held by the participants regarding communication competence of their relational other. The 20 items

in this scale were adapted to shift the focus from a conflict script to their own conversations with the person they note helps them the most regarding their fibromyalgia.

Phase II: Data Analysis

To answer RQ4, a multiple regression was performed to examine the relationship between communication competence, perceived communication competence of partner, and relational satisfaction on the perception of social support. If the independent variables: communication competence, perceived communication competence of partner, and relational satisfaction predict the dependent variable of social support, a second multiple regression will be performed by moving the social support item to an independent variable with the dependent variable coping. This was done to understand the relationship between coping and social support.

Phase II: Sample Description. In total, 150 patients completed the survey. All patients confirmed that a licensed physician had diagnosed their fibromyalgia. All of the participants were women, and the mean age was 48 years old. They were distributed by age group as follows: 3% were 18-25 years, 10% were 26-33 years, 18% were 34-42 years, 26% were 43-51 years, 33% were 52-60 and 10% were 61 and over. In total, 135 participants identified as European-American, while four identified as African-American, another four identified as Latina, six identified as Native American and one participant identified as Asian. Twenty-five percent of the participants held a bachelor's degree, and 23% had taken some college courses. Fifteen percent held an Associate's Degree, 14% had a graduate degree, 9% had taken some graduate classes, 8% held a high school diploma and 5% identified as other. When asked their work status, 62% reported not

working, 20% reported working full-time and 15% reported working part time. The final 3% were students. Thirty percent reported their annual household income was over \$91,000, 20% had a household income of between \$71,000 and \$90,000, another 20% had a household income of between \$31,000 and \$50,000, 16% had a household income of between \$51,000 and \$70,000 and 14% had a household income of between \$0-\$30,000. The survey was promoted nationwide, but the sample did not include every state in the US. Finally, a majority of the participants had been diagnosed with FMS over ten years ago (40%). Seventeen percent had been diagnosed 2-4 years ago, 13% 1-2 years ago, 12% 4-6 years ago, 12% 8-10 years ago, and 6% 6-8 years ago.

Chapter Summary

This chapter addressed the methodological framework that was used to answer the five previously discussed research questions. Additionally, the chapter discussed the research design, instruments, and data collection. The participants were given an incentive to participate through the chance to win one of three Amazon gift cards in both phases of the study. The role of the researcher was described in detail and the bracketing can be found in Appendix A. The validity of the qualitative phase was discussed through member checks and thick descriptions. The survey instrument was discussed in detail, and each scale was discussed for validity. The next chapter in this study describes the findings in detail.

CHAPTER FOUR

This chapter presents the findings of both the interviews and the survey analysis. The first phase in this study focused on interviews that were aimed at understanding the turning points women have with fibromyalgia and the impacts these turning points had on communication. This analysis provides a rationale for the research questions that were pursued in the quantitative phase of this research.

Phase 1 Turning Point Analysis

Seven women were interviewed using a retrospective interview technique which focused on turning points-in their illness and their relationships (For sample description see Table 3.1.) Narrative research illuminated common experiences during the interviews and a phenomenological perspective was used to classify these common experiences into themes.

RQ1: What turning points characterize women's experiences with FMS?

Both the turning point graphs, which can be found under Appendix D, and the interviews provided insight into what types of life events became turning points in the disease. After a thematic analysis, certain turning point themes were found in the data. Below is a table presenting those themes:

Table 4.1: RQ 1 Themes

| Turning Point Theme | Participants who experienced | Ranked Helpful, Detrimental, or Mixed |
|-----------------------------------|---|--|
| First symptom | All | Detrimental |
| Difficulty with Medical Community | All | Detrimental |
| FMS Flares | All | Detrimental |
| Finding ways to Cope | Kate, Moira, Jane, Charlotte, Brenda, Sally | Mixed |

FMS experience theme 1: First symptom. Due to the nature of the interview protocol, the first turning point that every participant discussed was her first symptom. All of the participants could recount an exact moment when a pain or numbness in their body no longer felt normal, and all categorized this as a turning point. Angela stated, “I was recovering from a very difficult pregnancy and delivery when I first noticed some weird symptoms. My hands were alternating between numb and tingly and I was exhausted all the time.” She later states, “I went to numerous doctors who all attempted to diagnose me with postpartum depression. I knew this was not the problem. I kept bouncing from doctor to doctor in hopes of finding someone, anyone that would listen to me but no doctor wanted to look further than my mental status.” All the while her symptoms were getting worse, and the pain moved from just her hands to her entire body. After a year and a half of seeing doctors who dismissed her illness, she was finally diagnosed with FMS.

Another participant who also placed the onset of symptoms as a turning point had a very similar experience. Brenda states, “It all began by having constant lower back pain, but then the pain started shooting around my body. It went from back, to pelvic pain, to shoulder pain, and pain in my neck and my migraines started getting much more rampant.” She saw countless doctors who dismissed her illness when the tests came back negative. Because the doctors repeatedly discharged her with no answers she stated that she started to feel like she was crazy. It was actually an aunt with FMS who first suggested it to her. Once she had a name for her illness, her general practitioner was able to test her for FMS.

Every participant reported difficulty with the medical community prior to diagnosis. A very similar timeline of events took place with each woman. They got to a point when the pain and/or fatigue would be too much, and they sought help from a doctor. Almost all doctors ran testing to rule out different types of illnesses ranging from autoimmune diseases to orthopedic issues. The doctor told the participant that it was most likely a mental illness after the tests came back negative and offered antidepressants. This resulted in each woman reporting this turning point and the subsequent turning points between pre-diagnosis and diagnosis as detrimental to their overall communication experience. Four were highly frustrated that they had all this testing and no results. Moira discussed this and said, “My diagnosis journey included an ER visit, two neurologists and blood tests. Finally they ordered multiple MRI’s which couldn’t find a cause for the numbness, burning and tingling I started having throughout my body.” Brenda had a similar experience. She states, “The doctor ran the standard tests, and they all came back

negative for autoimmune illnesses and thyroid issues. At a follow up appointment, I brought my infant with me, which I shouldn't have done. The doctor saw him and said I must have postpartum depression." Kate also had a similar experience. She states, "This journey was 5 years in the making. Internal medicine, podiatrists, and back doctors, which ordered, X-Rays and scans with no answers. I started feeling frustrated, alone, helpless, desperate." Once diagnosed, four of the women reported mixed feelings and a turning point in their disease. For two of the women, the diagnosis was rated as both helpful as well as detrimental to their overall communication. When asked why they gave this turning point two dots on the graph many said they were happy to finally have a diagnosis, but they quickly realized that this was an incurable chronic illness, which caused anxiety and depression. Jane states, "At first I had no idea what it [fibromyalgia] was, but when I went home and googled it, I wept. Having a diagnosis made me feel like I was not crazy, but I also felt distraught. The research I found online discussed how there would probably never be a cure in my lifetime which was very depressing." Angela also reported mixed feelings. She states, "While I hate the diagnosis, it was nice to know I wasn't losing my mind."

FMS experience theme 2: Difficulty with medical community. Another turning point that five of the women shared was frustration with the medical community before, during and after diagnosis. After an appointment with her rheumatologist, Moira felt extremely frustrated when her doctor told her to cheer up. She said, "In that moment, I wanted to smack her so hard. CHEER UP? If only it were that easy! I would love nothing more than to feel optimistic about finding treatment that will work well enough for me to

not feel like crap on a constant basis.” Jane also had difficulty finding a doctor that could actually help. She states, “I spent a lot of time at the doctor’s trying to get better only to have more and more prescriptions thrown at me. I was very unhappy wondering if I would get even worse at any moment.” Due to these experiences, the women started to distrust the medical community. This distrust led to feelings of stigmatization and limited communication. On the other hand, though, when each of three participants found a doctor who would listen and try to not only help but understand, she would plot this high on the turning point graph. Jane found a doctor who was extremely helpful through her interpersonal relationships. She states,

My doctor called for tests that no one else had performed. These tests revealed I definitely had Fibromyalgia, but I also had a mild case of Chronic Fatigue Syndrome, had Adrenal Fatigue and was hypothyroid. Other illnesses from high stress and crazy hormones also developed or had become worse. She put me on supplements and a thyroid medication.

Charlotte also eventually found a doctor willing to advocate for her. Her rheumatologist worked with her to find medications and supplements that worked. She states, “A fellow patient on my online support group suggested I take CoQ10. When I discussed this with my doctor, she actually did some research and suggested we up the dose.” Her doctor also discussed her FMS with her husband when he was being unsupportive. She said. “At one point my husband came to my rheumatologist appointment with me and started commenting negatively about my fibromyalgia. My doctor actually started lecturing him on the importance of support for my illness. This helped me quite a bit for a while, but

eventually he reverted back to his old ways.” Because of their difficult interactions with the health care system, the participants ranked this turning point as detrimental to their overall communication. The frustration they felt caused them to reduce their communication with others about their illness across a wide array of relationships. With a lack of understanding from the medical community, their husbands and friends were not always as understanding towards the disease.

FMS experience theme 3: FMS flares. Another type of turning point that was seen throughout the data was what the women called a FMS “flare.” According to these women flares are characterized as a quick onset and reoccurrence of severe symptoms. These flares can last for only a few hours or months. Triggers such as stress, acute illness, and overexertion, usually cause a flare, which is an individual experience for each patient. Eventually a patient’s flare will end, and symptoms recede back to lower levels that are seen as more normal. For five of the woman, a bad flare would cause a turning point in the disease where they felt their communication was impacted negatively. Three women were able to remember at least two times in the life course of their fibromyalgia when a bad flare caused an extremely memorable state of high anxiety or depression. Kate stated,

I remember one time I was having a bad flare and I lay down for hours to see if that would help me feel better. Not only did I still feel like crap I then started having restless anxiety that added to the flare formula and here I was antsy and in excruciating pain. Not a great combination. When these bad flares happen I feel like I’m wasting my life away.

Brenda could also recall a specific time a flare impacted her highly. She states, “One flare was particularly bad. I woke up with pain in both my hips, knees, feet, and elbows. It hurt my shoulders to carry my coffee cup down the hall at school. By the time I got off of work, I could hardly move. I was walking like a little old lady.” Participants also reported that it was very hard to describe a flare to their family members, colleagues, and friends. Jane tried to explain. She states,

On my bad days I wish I had no responsibilities. I feel bitter about getting up every day to make lunches... I just want be left alone to eat or sleep or cry whenever I want... I hope my husband would go to work and never come back. I hate the guilt I feel because I am not being a good wife. If I were alone, I wouldn't feel responsible for the cleaning or cooking. I wish my friends would leave because they are insufficient anyway. They are absent when I need them and they never understand my fibromyalgia.

Sally also attempted to describe a flare. She said,

I usually explain my flares by how they feel. For me, it starts with strain. My muscles feel stiff. Then the pain starts throbbing in the area hurting in that moment. It is a very deep ache, like having a flu but in my bones and muscles. It can also be a stabbing pain - like an icepick being speared and turned into my hips or ankle. All of these sensations torture you until you want to escape your own body.

Throughout the turning point graphs, flares would be rated as detrimental to extremely detrimental because they felt they were barely able to survive, much less

communicate competently. Alternatively, days when they could manage their symptoms and engage in normal daily life were also placed on the turning point graph and were ranked as helpful in their relationships. For example, one participant mapped a Halloween when she was able to take her children trick or treating. Kate states, “I remember celebrating the fact that I walked the neighborhood and didn’t have to be picked up! As family and friends came over and we started to get the food out and the kids started to get ready, I started to get excited and at the same time really nervous. I kept thinking would my body fail me? Would I just go for it and pay later? But I did it!” Vacations were also discussed as turning points because the women were able to have fun with their families and were able to communicate better with others because of this. Unfortunately, vacations and events were usually placed only midway between high and low because when the participants would push to do something fun, they would often cause a flare. Moira states, “But the trip did take a lot out of me. I was so sore, I could hardly move. The fatigue left me feeling nauseated. I couldn’t take my oldest daughter to the bus in the morning. I think all I really managed to do that day was feed myself and the girls and put my youngest down for bed.”

FMS experience theme 4: finding ways to cope. A final turning point that six of the women placed on their graph were different strategies they used to cope with the illness. Overall, these strategies were seen as helpful to their communication as they were usually able to diminish the symptoms momentarily. Two coping strategies discussed were changes of either a medication regimen or lifestyle in order to help with their FMS. Charlotte was a unique case where her FMS was brought on by a heart surgery and an

allergic reaction to the drug family of statins. She argued with her doctors to take her off of them. She states, “No doctor would diagnose it as a statin problem. My primary care physician finally recommended I stop taking the Lipitor after I kept complaining but my cardiologist wouldn't let me do that so I did my own research and asked if I can take CoQ10.” She found that CoQ10 was extremely helpful in reducing her symptoms, and therefore ranked this turning point as helpful for her communication about the disease as well. She stated that when she had a reduction in symptoms, she could better articulate to her husband what she was feeling and what she needed.

Kate joined two pain programs during the life course of her disease. When she joined, she ranked this moment as helpful on the graph. She explained that she was excited and hopeful that each program would make an impact on her symptoms and that gave her more motivation to want to communicate about the illness. She states, “I was really excited to get into it. I heard great things about it. The success rate was very high providing you always follow what you learned and made it a change in your life and don't fall back to your old habits.” Unfortunately, this program had serious adverse side-effects. A few months into the regimen, the medication caused her to start contemplating suicide. She states, “I gotta tell you, my meds were seriously making my life Hell. I didn't realize how truly bad my crisis was until I started really contemplating suicide on a daily, almost hourly basis.” This moment was ranked as extremely detrimental to her communication. Because she was suicidal, she stated she rarely discussed her FMS with her spouse. Once she realized this may be caused by the medication, she called her personal doctors and the pain program doctors and was immediately taken off the

medications. Others, like Angela, also placed on their graphs a bad side effect from a drug. Angela's doctor changed her medication, and it caused her to itch all over. She said, "My doctor had switched my medication so I anticipated that I may have to deal with new side effects. I never imagined that the side effect would be itching! Very weird. I feel like my whole body is on fire and I just want to scratch everything." When the participants would experience detrimental side-effects, their communication would suffer because they would not want to burden their spouses with new negative information.

Another coping mechanism used by two of the participants was attempting a diet change after performing online research. Jane states,

I decided to try diet change again but this time I was stricter. No artificial ingredients, no caffeine, gmo, hfs, etc. and as little processed foods as possible. I was trying to be as clean as I could afford. I even cleaned out the house of chemicals, hair products, tore up carpet you name it. I went all out. This time it made a noticeable difference.

Any changes that helped alleviate the symptoms of FMS were seen as helpful to the participants' ability to communicate.

Because the participants had to be their own advocates with the medical community, this caused them to develop coping strategies such as doing their own research, joining support groups, and learning how to balance their lives and their illness. A turning point in the illness for six of the seven was when they discovered a coping mechanism that would help. These turning points were rated as mixed because while they may help with their symptomology, and thereby help them communicate about the illness

better, they found some mechanisms would create communication problems which led to feelings of guilt. One coping strategy that was discussed throughout was learning how to balance their time and energy.

Sally discussed finding balance. She notes, “How I have to live my life has been forced to change. I get worn-out very easily now. I hurt. I don’t have the luxury to run around all day, doing whatever that comes to mind. I must plan and make choices. Dished or Cooking? Shopping or an evening out? I cannot do everything I need to or used to do in a day.” This strategy, while it helped the symptoms of the illness, caused issues in their relationships. Moira discusses this when she says, “Keeping everything balanced is extremely tough. I am a mother of two small children, and can’t just say, ‘Good luck’ and vacate my life on one of my bad days. Saying no is difficult.” Brenda experienced struggles when trying to communicate her need for balance to her friends and family as well. She notes, “I battle my anxieties when my friends and family ask over and over and over and over again why I don’t join when they do something athletic, or whatever asks more of my consciously managed schedule.”

Another coping method that was used was going outside the marriage to find support. This support was usually found through other FMS patients or medical practitioners such as therapists. At one point during the life course of the illness, Angela’s husband pushed her to join Twitter. There she found others who had FMS. She states, “My husband peer pressured me into getting on Twitter as way to connect with other people who had fibro. I find it’s a great resource to connect with others and sometimes just make me laugh.” Jane also turned to the internet to find support. She joined online

support groups, wrote on FMS forums and read other patients' blogs. She says, "There is a reason chronically ill people look to support groups and organizations. It is because we can be with others who are experiencing the same thing. Feeling like you aren't on your own is important to healing in my opinion." While these help, for her, they are not enough. She notes, "No matter how many blogs I read, or support groups I join sometimes I still feel alone." This highlights the complexity of this turning point.

Charlotte, too, joined both a virtual support group as well as a face-to-face support group. She says, "I went online and started doing my own research and through that I found support groups. I started participating in an online support site and attending a local support group." Unfortunately though, her support groups slowly started to fall apart. She says, "I missed one meeting and haven't heard about any more. I haven't searched for any more support groups because I still need support but I just can't find the time."

One final area that helped the women cope with their illness was through work. Overall, the participants felt that work was helpful in managing the disease as it gave them additional social support and something to focus on other than their disease. Charlotte states, "I did find that my job helped me quite a bit." Jane's job also gave her a sense of satisfaction and purpose, so when she had to quit and go on disability because her symptoms were too severe, she was greatly affected. She notes, "I had to reduce my hours, and eventually quit my job and in some ways my life to just sit home and be sick. I felt like a disappointment. I felt frail and mortified that my body could not do everything my heart wanted to do. I gained weight, lost faith and became furious." For some, going

on disability was seen as a positive outcome. At first, Kate tried to see it as time to heal and focus on getting better. For others, like Charlotte and Jane, it made them feel like they failed and placed a financial strain on their families. In order to cope with this change, many of the women tried to find low stress/low impact hobbies that gave them satisfaction. For Jane, she participated in Warrior Dash races. For Sally, she turned to her love of music and found ways to use it as therapy. Moira started to focus on her love of video games and science fiction. The only participant who did not discuss coping strategies specifically during the turning point interview was Angela. There may be many reasons she did not discuss it, but she was also the only participant who was still able to work the same full time job she had before she was diagnosed with FMS. Also, she had a very strong support system through both her family life as well as through her colleagues. As a teacher, she stated she had to regularly take sick days when she would experience a flare, yet her cohort of colleagues would help so her students did not fall behind. Because she was able to work, her identity changed less after her diagnosis. She was able to concentrate on her goals separate from the illness which provided a coping strategy in itself. Angela's support system at home was also very strong. She discussed her husband and his support in high regard and stated that her two sons would help with the chores when she was unable to due to flares. Because her family was so supportive, she felt able to communicate openly, which helped her cope with FMS.

Overall while the women had unique experiences with FMS in regards to symptoms, triggers to flares, and the timeline of the disease, they also had extremely

similar experiences in their fight toward a diagnosis and in finding ways to manage the disease.

RQ 2: What turning points characterize women’s experience in finding barriers to and the need for support with a relational other? After each participant was interviewed about her experience with FMS, she was also asked how she discussed her illness with a significant person in her life. All women were married, and all picked to do a turning point analysis of their communication with their husbands. Below is a table highlighting the themes that were found:

Table 4.2: RQ 2 Themes

| Turning Point Theme | Participants who experienced | Ranked Helpful, Detrimental, or Mixed |
|----------------------------|--|--|
| Guilt | Angela, Kate, Sally, Jane, Brenda | Detrimental |
| Aloneness | All | Detrimental |
| Instrumental Support | Kate, Moira, Angela, Jane, Brenda, Sally | Helpful |

Social support theme 1: Guilt. Four participants discussed feelings of guilt because they placed so much responsibility on their husbands. Kate states,

My husband does it all... he takes care of the cooking for the family, he drives everyone to wherever they need to go, he does the errands, he is the person everyone turns to. I know I shouldn’t be envious, but I want to fill that role. The

problem is, the fibro makes it so I cannot do what he does. I'm not dependable.

I'm unpredictable. If it wasn't for my husband, my family wouldn't function. I feel guilt-ridden that I cannot do more, and that I didn't choose to do more when I was working crazy hours.

Moirá had similar feelings. She comments,

I feel extremely guilty about the effect my fibromyalgia has on my husband. He didn't ask for this. We've pretty much been coping with this for 6 1/2 of our 7 years of marriage. While I think I pull my weight, I feel guilty because I feel like life has cheated him out of an equal spouse. I know it's not my fault and that I didn't ask for this either, but it doesn't always keep me from feeling guilty.

The guilt does not just stop at the feelings of being a bad partner around the home; it also extends to activities outside of the home too. Angela said, "I feel guilty for not wanting to do anything on the weekends because I am in so much pain. Fortunately for me, I live with a magnificent group of guys who indulge me and recognize what I'm going through." Guilt was also felt for being the cause of worry in the household as well. Sally said, "As my illness has progressed my husband and children definitely see the symptoms now. They see the damage and suffering. I can see how much it saddens and scares them and it's heartbreaking for me to watch them go through that."

This guilt caused the participants to have troubles communicating openly with their partner and others, which caused them to rank these points as detrimental. Sally said, "It can be hard to share, especially with family when you see how it can scare them and how much they worry for you. I never want to burden anyone. Nor do I want to look

pitiful and broken.” Kate also discussed how her communication suffers because she has FMS. She notes,

Because of my health issues I am struggling to make it through every day while actually trying not to be selfish/ self-absorbed...I feel like my husband is trying to support me and to not complain about the situation – in the end we both are trying to keep from building up resentment: The healthy spouse because they have to do everything, and the unhealthy spouse for not having as much self-sufficiency as they would like.

When Jane discussed her reasoning for not always confiding in her husband, she discussed more that she was looking for permission to complain without judgment. She says, “I need him to listen to my issues without judging me for having them, and since I don't feel it truly possible that others *won't* judge I rarely discuss my thoughts and feelings and discussion about my pain. I am trying to find permission to say and feel everything I have been keeping secret.” Because she felt she couldn't discuss her feelings with her husband, she started saying them out loud in the car and said it helped her greatly. She states, “The world didn't stop rotating. My boss didn't fire me. No one judged me. My husband did not ask for a divorce.” Kate also discussed why it was difficult for her to confide in her others about her FMS. She notes, “I still have a hard time talking about all of my conditions. I don't want others to feel sorry for me.”

This worry and guilt also lead some of the women to feel like a bad parent. One example of this was highlighted by Moira who states, “And the guilt. Oh the guilt of having to say, *you are hurting mommy, please stop. Or I'm sorry I can't help you right*

now because I am so tired.” Jane mentioned this in one of her turning points as well. She said, “I think my kids are getting cheated out of my best because I’m too exhausted or sore to do everything I want to with them.” Jane also discussed her feelings on parenting with FMS, and the guilt it caused her. She said, “I strive to have my kids participate in activities, having a social life and I adore watching them from the sidelines or from the audience. But because of fibro, I constantly feel partially involved. Partially invested, partially interested, even partially coherent.” Kate also discussed how FMS makes it difficult to feel like a good parent. She notes, “The pain, mental and physical, is not a small issue in parenting. I can’t expect my kids to know what I’m going through and how it affects my behavior and communication.”

Not all participants had strong support systems, which would cause the detrimental effects on their communication to be compounded. Charlotte’s husband and son could not understand her needs or offer support. She states, “My family did not offer much support. My son’s ex-girlfriend actually gave me more support than my husband or son because they want me to be mom and to do the chores around the house, which I can’t do. So it’s hard for them to let go.” Other husbands would be supportive overall but would have lapses in judgment and forget their wives were no longer as capable as before. Jane had a turning point on her graph where her husband was unsupportive when the rest of the graph showed him as an overall helpful and supportive partner. One time he did not check with her before agreeing to let their daughter stay home from school when she did not need to. She said, “She was certainly healthy enough for school, and I

was dealing with the worst back pain, struggling the entire day to play with her all the while becoming more and more angry with him as the day continued.”

Social support theme 2: Feeling alone. Another theme found throughout the turning point graphs and interviews was the feeling of being alone. While the women identified some sort of support structure, whether effective or ineffective, all also discussed how the disease was extremely isolating. These feelings of loneliness would have a detrimental effect on the participants’ communication. Angela states, “Usually I feel like fibromyalgia is just one immense solitary fight and only my obnoxious personality and pigheadedness keeps me fighting it. Everyone else is not as obnoxious as I am, which is why being sick with this disease is so difficult.” Jane also said something similar, “Even when I am happy, deep down there is a pesky voice that tells me I am all by myself and surrounded by people who will never understand”. Sally discussed why it is easy to feel alone in her battle with FMS. She notes, “It’s hard being raw, completely open and honest, to force others to understand the very severe reality of what fibro is and how it manifests not only in my physicality, but psychologically and spiritually. I don’t know about everyone else but I want to protect them.” Others discussed their loneliness as a byproduct of having an invisible illness. Angela said, “Dealing with a chronic illness daily is bad enough, but when that chronic illness is invisible it is terrible beyond words.” Jane went further to explain why an invisible illness makes it harder to seek help. She states,

To discover and share affection, companionship, kindness, wealth, home, sustenance, work, and pleasures. All these are a far more wholesome experience

when it is with others, and for others. Illness, especially INVISIBLE ones, steal away some of that experience. Even in areas of support and groups of other sufferers. The ability to identify is beneficial but not thorough.

The illness also creates issues for the participants because of the way the symptoms change day by day, which causes them to have a hard time making plans. Kate discussed this when she said, “They want a dependable *YOU*”, not this occasionally emotional, sometimes unreasonable/ unreliable/ delicate person. Sure we have moments of normalcy and we welcome those times, but sufferers understand that there are going to be the ups and downs.” When they would not be able to make plans, this would cause their loneliness to increase because they felt that their lives were simply passing them by, and they were losing connections to those they loved. Yet, spending time with friends and family would also be a stressful event. The women discussed how when they were finally able to attend a social event they would be questioned as to where they had been or what was keeping them away. On the other hand, they felt pressured to say yes to some events purely out of fear that if they kept saying no, they would not be asked to future events. Also, social events usually would cause anxiety because the participants would worry it would cause a flare the next day.

The anxiety over the invisibility of their illness also extended to how strangers saw them. Some of the women felt they had difficulties, simply because their illness was invisible, when they would use services for which they were eligible. Angela placed her acquisition and use of a handicap tag on her turning point graph as neither helpful nor detrimental. When she discussed it further she said,

When I received my permanent disabled parking license plates for my vehicle, I frequently feel guilty for using them because of the stares people would give me when I walked into the store. The glare that makes you feel you need to explain why you venture park in that hallowed space. I just want to scream yes I look normal! I don't look like the stereotypical person who is permanently disabled!

Please stop looking at me as if I'm in the wrong.

Sally also discussed getting her handicap placard in her turning point graph and had a very similar reaction as Angela. She states, "I didn't want it [the placard]. It is yet another sign of being incapacitated by a disease. Others will watch me get leave my car and go into the store. All the while, giving me a judgmental look that definitely says - She's clearly not handicapped. She can walk!" Yet at other times some of the women were glad their illness was invisible. This turning point was seen as neither helpful nor detrimental to their communication because it was both. For example, with a handicapped tag, they were able to accomplish more while using less energy; yet, they felt it had a detrimental impact because they were now seen as inauthentic and different. This caused them to reduce their communication even with strangers. Brenda discusses the complicated nature of this turning point, "Occasionally it's nice to be able to act like you are normal. Nobody knows I am ill so no one looks at me when I go out. Every now and then I feel like it would be a good if fibro was visible so people would understand me better, but as a whole, I'm glad it's not." Sally discussed this as well. When asked why she likes to hide her illness, she states, "Why hide it? I'm proud and persevering. I don't want sympathy. I want to act and look 'normal'." She mentioned how sometimes it's nice

to fit in, but in doing so she had to learn how to hide her illness, which takes a toll on her. She says, “I make an effort to be conscious of when I grimace or cringe and to hide not just my normal pain but the pain I receive when others touch me. When I need a break to give into the torture or push past fatigue, I find a room to take a moment be isolated and simply breathe.”

Social support theme 3: Instrumental support. Throughout the data analysis, it was rare to find a woman who did discuss the use of open communication when talking with a spouse. When they were able to confide in their husbands, the participants ranked this turning point as helpful. Moira and Sally were the only participants who spoke of how their husbands listened in regards to how they were coping with FMS. Moira notes, “My husband has been very sympathetic and helpful. He has listened to me and tries his best to understand. Not once did he say ‘get over it’ or ‘it’s all in your head’.” Sally said something similar when discussing how she and her husband communicate about her illness. She notes, “I talk about my fibro with my spouse. He is the only one I truly discuss every moment of my journey with.” Yet, she goes on to explain why she only openly communicates her needs to her husband. She states, “Discussing fibro can be challenging for so many reasons but it’s also strenuous. If I’m going devote my time and energy to talk about my illness, it has to be with someone that will actively listen and really hear me. My husband does.” What the women did discuss when referencing communication with their husbands was how they helped and pushed them to seek new treatments. This included accompanying them to the doctor’s office or driving them to testing. This again was ranked as helpful to their communication when the spouse was

perceived as a positive influence. Whenever Angela discussed her doctor's visits, she would also mention that her husband was there. Moira discussed how her husband would wait in the lobby whenever she had testing done, and Brenda's husband was the reason she kept searching for answers from the medical community. She notes, "Eventually my husband bugged me enough that I made a doctors appointment, simply because I wanted to make him happy."

Something else that was discussed throughout the turning point graphs were the times their husbands were able to help by doing. Whether it was running errands, cooking, or driving, the women described how their husbands were supportive through their actions. This instrumental support was ranked as extremely helpful for the participants. For example, both Charlotte and Kate discussed how their husbands would do the cooking when they could not. Kate also discussed how her husband helped to keep the family going. She states, "I am fortunate that I have a husband who takes magnificent care of me. He does everything for my children and me. He does all the cooking, cleaning, driving, and care-taking."

The women also discussed how their husbands would take care of the majority of work during social events too, as well as participate in events they were not interested in to support their wives. At a Fourth of July cook-out, Kate's husband did more of the work so that she could relax and have a good day. She states, "Those dark clouds opened up and the light shined through. I permitted myself to just relax and my husband took care of the kids and me and I was able to enjoy the time with old friends and family. I had a wonderful time!" Jane felt supported when her husband simply decided to join in her

hobbies. She was a former marathon runner and now does warrior dashes to feel a similar sense of accomplishment. Because they are more of a team effort, they are easier for her to do. At one race, she asked her husband to join her team. She says, “After one of the races, my husband was obsessed. He got home and ran to the computer to find more races! It felt nice to have my husband join something that had just been ‘my thing’ up till then.” Angela discussed how her husband decided to join a weight loss program with her. She states, “My husband and I joined weight watchers, and we took our new diet one day at a time. It was really great having him there, giving me motivation to do well, and helping me eat better.”

Finally, while the women were asked to discuss just one individual when discussing their turning points, they had a hard time limiting it in that way. All would include, if not actual turning points, at least discussion about their children or parents during the turning point analysis. When each participant was asked why they had a difficult time limiting it to one person, some would say that they need help from more than just their husbands. Angela discussed how her family all worked together to pick up the slack. She said:

I can't restate enough how blessed I am to have such a wonderful support system in the men in my family. My husband makes sure that most of the chores are done, and my oldest son helps pick up the slack by doing other chores whenever he can. My youngest son helps by offering to give me a massage. I am truly lucky with my guys!

The only participant who did not discuss this theme was Charlotte. Throughout all of the interviews, Charlotte's family was the least understanding of FMS and the ways it forced her to change. While her husband would help with cooking, she stated that he did so begrudgingly. In order to help him understand, she asked her rheumatologist to help explain the support she needed around the house. While this interaction helped, she said it was only a matter of time before he reverted back to thinking she could do everything around the house as before the diagnosis. This assumption led to strong feelings of guilt which caused her to use more closed communication with her husband and caused her symptoms to worsen.

RQ3: How are relational turning points associated with illness turning points? Overall, there was very little crossover between the two turning point graphs. Rarely would a point on the illness turning point also be found on the relational turning point. One reason for this may be because the women felt that they were alone in their illness. The women discussed many times that FMS made them feel ostracized from enjoying time with friends and family. Sally discussed this when she said, "It is hard for me to share what upsets me with others. I would rather conceal it. Disguise the pain, the exhaustion. Disguise my tears - cry in the bathroom, alone." Moira also discussed why at times she feels alone. She states, "The way others will occasionally treat us because of our illnesses forces us to focus on the negative feelings we so often shove down and ignore. When we're ignored, cast aside, or stereotyped negatively, it's so easy to withdraw and allow thoughts of what's broken to take over." Retreat was something the women seemed to do whenever they discussed a flare. While many of the participants were

discussing their FMS flares, most discussed the side-effects a flare would bring on. Kate, Jane, and Sally mentioned how their depression and anxiety would get much worse during this time. Kate discusses how she has to try to fight to try and overcome the mentally draining aspects of a flare. She states, “I have to battle these demons, the anxiety, the depression, the little voice murmuring in my ear that my pain is too strong and I can’t fight it.” When the depression or anxiety were heightened, the participants were much less likely to seek support through open communication. For example, Jane states, “I just want to be left by myself. Left to eat or sleep or cry whenever I want.”

Another reason there may have been little overlap was due to their difficulty in explaining to their husbands exactly what they needed from them. Communication was discussed frequently as something made difficult by the disease. Instrumental support was discussed most frequently and most positively, whereas emotional and informational support were rarely discussed. This highlights a communication issue found in this population. Sally discussed why communication is so difficult for her. She states, “I need to be the cornerstone and the strength of my family. I don't want them to worry. I feel frail when I talk about fibromyalgia. I also get tired of people thinking they can heal me - they can't heal my fibro any more than I can so I wish they wouldn't try, it's frustrating for me.” Another issue that arises is what the women classified as “fibro fog.” This was when they could not think coherently. Words would escape them and even simple tasks would become difficult to think through. Moira explains this fog when she notes:

When I am in the heart of fibro fog most of my words don't actually formulate into coherent thoughts. Long ago I may have been able to form my thoughts

effortlessly. Now, they fly around in this foggy space as I try to hold onto them. It is difficult for me to find, or as I say, make words.

Sally also explains fibro fog. She says, “I forget what I was talking about in the middle of a statement. I have to stop and think about what I was just saying, find my train of thought and start again.” According to the participants, this fibro fog makes communicating even more difficult than it already was. This in turn may be one of the reasons the participants feel alone and did not have many overlapping turning points between communication and illness trajectories.

One theme that did emerge between the two turning point graphs were the occasions where their husbands helped so that they could enjoy a vacation, holiday or event. As stated previously, Kate placed the Fourth of July on both her FMS graph and her communication graph. She placed this event in both graphs because it was a day where she felt her FMS allowed her to take part in socializing with friends, but she also felt that it wouldn't have been possible if her husband had not been there to help. Having support from him allowed her to pay attention to her symptoms, and when she needed to leave. She states:

When my pain was too much to handle, I looked at my husband and he simply knew exactly what I needed and we said goodbye. He drove us home and I rested for a while and my husband took care of the dog. Once I was more rested, we all went to our neighbors for the annual fireworks and then back home for the night.

Phase 2 rationale. According to the sequential exploratory design, the turning point graphs and the interview findings were analyzed to inform the questionnaire

(Creswell, 2010). The qualitative data were rich and highly informative, yet some areas of inquiry need to be explored further. One area that requires analysis on a larger scale is that of factors that improve the likelihood of receiving social support and whether such support improves coping. While the participants discussed how their husbands helped them by taking over the household duties and serving as a support system during social gatherings, it is unclear if this was sufficient. Additionally, while the data showed that this instrumental support was a great help for the participants, they did not discuss emotional support or informational support nearly as much, nor did they provide a great deal of insight into what factors enhance their chances of receiving social support.

Therefore, from this data the variable *social support* emerged as a key concept as both an outcome of competent communication and a predictor of improved coping. Because it includes several types of social support and is focused on the illness context, the measure used was the Medical Outcomes Study-Social Support (Sherbourne & Stewart, 1991),

Communication competence also emerged as an important concept. As stated, it appears that social support is gained as a result of effective and appropriate communication by both the self and the relational partner. This is closely related to the theme of feeling alone. The participants stated reasons for not reaching out (i.e. did not want to cause further anxiety for spouse and/or the illness or symptoms were too difficult to explain), yet they did not discuss what impact this had on the relationship or further communication. To understand barriers to finding social support, we must first understand how well the relational partners communicate with each other. In order to study communication competence, the variable was split into two: communication

competence of self and perceived communication of the partner. Communication competence of self was studied using the Interpersonal Communication Competence Scale (Rubin & Martin, 1994) and perceived communication of other was studied using Perceptions of Communication Appropriateness and Effectiveness Scale (Canary & Spitzberg, 1987).

A key variable that could impact the achievement of social support is relationship satisfaction. While the participants usually discussed their marriages in a positive tone, the data analysis revealed that FMS also causes a heavy strain on the relationship. This may lead to less relational satisfaction, which may impact how well social support is offered and received. Therefore, the variable of relational satisfaction was examined as a predictor of social support and coping. This variable was measured using a single item because input of the relational partner was not available, which the most widely used marital satisfaction instruments require.

Finally, after the qualitative data analysis, questions still lingered regarding how the patients were coping with FMS. While individual coping mechanisms were discussed in the interviews, there was little discussion of how communication competence, social support, or the relational satisfaction helped them cope with the disease. The final variable to be examined in the quantitative survey will be coping. This variable was measured with a single question regarding coping changes over the last six months.

Phase II: Survey Analysis

This phase utilized multiple regression analyses to test two research questions. The first research question focused on the extent to which communication competence of

self, perceived communication of relational partner, and overall relational satisfaction predict social support. The second research question focused on the extent to which communication competence of self, perceived communication of relational partner, overall relational satisfaction and social support predict coping. The first multiple regression was conducted with the two communication competence variables and overall relational satisfaction as predictors of social support. A second multiple regression was then performed using the two communication competence variables, overall relational satisfaction and social support as predictors of coping.

RQ 4: Communication and social support. The fourth research question asked, how well do communication competence, perceived communication competence of partner, and relational satisfaction predict perceptions of social support. When asked who helped them the most when looking for emotional support, 49% of the participants stated that their significant other helped the most, whereas 31% stated a friend helped the most. When asked who helped them the most when looking for instrumental support, 79% stated their significant other helped them the most, and only 8% stated a friend helped the most. Also, 72% reported their significant other as helping them the most overall. These responses are similar to the findings with phase one and validates the examination of perceptions of the relational partner's communication competence and relational satisfaction as predictors. In the first multiple regression, the outcome variable was perceived social support from the significant other. The predictor variables (communication competence, perceived communication competence of relational other, and overall satisfaction with the relationship) were entered into a multiple regression

analysis in decreasing order of bivariate correlation. The results are summarized in the tables below.

Table 4.3: Predictors of Social Support

| Step | Predictor | R ² ch | β |
|------|----------------------------|-------------------|----------|
| 1. | Perceived Comm. of Partner | .678*** | .823*** |
| 2. | Overall Satisfaction | .090*** | -.412*** |
| 3. | Comm. Competence of Self | | .002 |
| | R ² | .768*** | |

Note. N=150. *p <.05, **p <.01, ***p <.001

Table 4.4 Bivariate Correlations of Independent Variables with Social Support

| | Social Support | Perceived Competence | Satisfied with Relationship | Competence of Self |
|-----------------------------|----------------|----------------------|-----------------------------|--------------------|
| Social Support | | | | |
| Perceived Competence | .823*** | | | |
| Satisfied with Relationship | .782*** | .684*** | | |
| Competence of Self | .421*** | .429*** | .382*** | |

Note. N=150. *p <.05, **p <.01, ***p <.001

The first research question asked how communication competence of self, perceived communication competence of the relational other and overall satisfaction with the relationship affected perceived social support. Both perceived communication competence of the husband, in this case, and overall satisfaction with the relationship were highly significant predictors ($p < .000$), but communication competence of self was not significant. Perceived communication competence of the significant other and the

overall satisfaction of the relationship together predict 77% of the variance in perceived social support.

RQ 5: Communication, social support and coping. The final research question asked how well communication competence, perceived communication competence of partner, relational satisfaction and perception of social support predict perceptions of coping with FMS.

In the second multiple regression, independent variables (communication competence, perceived communication competence of the relational partner, overall relational satisfaction, and social support) were entered into the analysis in order of their bivariate correlation with coping. The results of the second multiple regression analysis are summarized in the tables below.

Table 4.5: Predictors of Coping

| Step | Predictor | R ² ch | β |
|------|----------------------------|-------------------|-------|
| 1. | Comm. Competence of Self | .087*** | .295 |
| 2. | Perceived Comm. of Partner | | .081 |
| 3. | Overall Satisfaction | | -.068 |
| 4. | Social Support | | |
| | R ² | .087 | |

Note. N=150. *p <.05, **p <.01, ***p <.001

Table 4.6: Bivariate Correlations of Independent Variables with Coping

| | Coping | Perceived Competence | Satisfaction | Competence of Self | Social Support |
|----------------------------|--------|-------------------------|--------------|-----------------------|-------------------|
| 1. Coping | | | | | |
| 2. Perceived Competence | .17* | | | | |
| 3. Satisfaction | .18* | .68*** | | | |
| 4. Competence of Self | .30*** | .50*** | .38*** | | |
| 5. Social Support | .18* | .82*** | .78*** | .43*** | |

Note. N=150. *p <.05, **p <.01, ***p <.001

The second research question asked how coping was affected by communication competence of self, perceived communication of their significant other, overall satisfaction of the relationship and perceived social support. Only communication competence was a significant predictor, explaining 9% of the variance in coping.

Chapter Summary

In this chapter, the findings were presented.

Phase 1. In the first phase, the analysis revealed themes within each turning point analysis. The first research question focused on the participants' experience regarding FMS and communication. Four themes emerged: first symptom, flares, difficulty with the medical community, and coping methods. The second research question focused on the communication changes between the participant and a significant other and how it was impacted by their FMS. Three themes emerged: loneliness, guilt and instrumental support.

Phase 2. In the second phase, two multiple regression analyses were performed to answer research questions four and five. Additionally, descriptive statistics from one item

in the survey were analyzed to validate the study's design. The fourth research question asked how communication competence of self and perceived communication of the partner, as well as relational satisfaction affected perceived access to social support. The analysis revealed that perceived communication of partner and relational satisfaction, together, explain 77% of the variance of social support. The fifth research question asked how communication competence of self, perceived communication competence of other, relational satisfaction and social support affected coping. The analysis revealed that only communication competence of self predicts coping, explaining only 9% of the variance.

The qualitative and quantitative research findings coincided on many items. Both phases found that instrumental support played a large role in the social support received from their spouses. Another finding was that coping is primarily an individual task and the participants' partners are not perceived as assisting in this task. This pattern may explain feelings of loneliness and guilt. The next chapter will discuss how these findings overlap with previous research and will discuss how these findings may have a theoretical basis.

CHAPTER FIVE

This chapter provides a discussion of this study's findings for both parts of the mixed method research, which includes the turning point analysis as well as the statistical analysis of the survey data. Both sections of the research focused on how the women with fibromyalgia sought and received social support. The theoretical and practical implications of these findings are discussed along with the limitations and strengths of this study. Finally, this chapter concludes with a discussion of the future research opportunities that may expound on this study.

Discussion of Findings

The first three research questions focused on the turning point analysis, and the final two focused on the survey analysis. The research questions from the turning point analysis focused on the themes that emerged through their turning points with both the disease and with a significant other. The research questions for the survey analysis focused on how the participants received social support and the impact it had on coping.

RQ 1: Turning points with FMS. The first turning point graph data revealed four themes: first symptom, difficulty with medical community, FMS flares, and researching and coping strategies.

FMS experience theme 1: First symptoms. The first theme the participants discussed was their first symptom. None of the participants had the same experience at

the onset of symptoms. These symptoms ranged from back pain, foot pain, and tingling and numbness in the hands. This theme highlights one of the problems inherent in this disease. These symptoms, at first while irregular, are neither life threatening, nor unique. They may also be symptoms of a myriad of diseases such as depression or anxiety disorders. According to Arnold (2008), FMS is strongly associated with these disorders and because of this association, patients can be incorrectly diagnosed with a psychological illness rather than FMS. This was seen in the turning point analysis as well. Angela's FMS symptoms started after her difficult pregnancy, and because of this, her doctors diagnosed her with postpartum depression. In a study by Choy et al. (2010), patients experienced multiple fibromyalgia symptoms including the most reported: pain, fatigue, sleeping problems, and concentration difficulties. Again, these symptoms may lead doctors to look at different illnesses such as RA or MS.

Choy et al. (2010) also found that the patients waited on average almost a year after experiencing the symptoms before discussing them with a physician. When asked why they waited so long, the patients listed reasons such as waiting for the symptom to go away, wanting to manage the symptoms themselves, and not wanting to take medications. Because these symptoms are non-life threatening, the patients did not feel the need to rush to the doctor. The participants in the present study also discussed using the "wait-it-out" method with their symptoms. They thought that these symptoms were acute and that with patience and time, they would go away. Waiting, however, leads to communication issues when finally seeking medical advice. Because the patient has been experiencing symptoms for on average a year, according to Choy et al., they are now

worried and frustrated, which impacts the way in which they discuss their experiences with a doctor. Another issue is that most patients start with their primary-care physician rather than a specialist, which may also lead to misdiagnosis, further confusion and frustration. This phenomenon was seen in the turning point interviews. For example, Kate spent five years seeking a diagnosis and in that time saw five different doctors whose specialties ranged from podiatry to internal medicine. The complicated nature of FMS as well as the communication issues between the physician and patient lead to the second theme found in the turning point data revolving around the illness. With these difficulties in mind, it is not unreasonable to see why the participants would plot this turning point detrimental to their overall communication about the illness.

FMS experience theme 2: Difficult diagnosis. The second theme discussed by the participants was difficulty in being diagnosed from by the medical community. Research shows that what the participants experienced in finding a diagnosis is not outside of the norm. Perrot et al (2012) surveyed over 1,600 physicians in six European countries, Mexico and South Korea and found that around 80% had seen a patient with FMS in the last two years, and 53% of physicians had difficulty in diagnosing FMS. Additionally, 54% said their training with FMS was inadequate, and 32% felt they were not knowledgeable about FMS. Part of the problem is patient communication. Sixty-four percent agreed that the patients found it difficult to communicate about their symptoms. Finally, 48% of doctors surveyed said they were not confident in differentiating FMS from conditions with similar symptoms. Choy et al., (2010) found that it took an average of 2.3 years to receive a diagnosis, and on average the patients discussed their symptoms

with 3.7 physicians before they were diagnosed. These discrepancies, which were also found in the turning point data, caused the participants to distrust their doctors, as they felt forced to take their illness and treatment into their own hands. This is discussed more in theme four. One example of the frustration felt by the participants was Angela, who felt that when she would want to discuss a symptom that did not seem related to her FMS, she found her doctors would just blame it on the illness and refuse to examine the problem more.

Another issue revolving around the medical community for these participants was the great number of doctors they needed to see throughout their illness trajectory. This is not an uncommon phenomenon. Hughes et al. (2005) found that on average patients with FMS had considerably higher rates of doctor visits, prescriptions and testing than the control group. By the time of diagnosis, FMS patients had, on average, 25 doctor's visits and 11 prescriptions a year compared to the 12 visits and 4.5 prescriptions a year in the control group. Hughes et al. also found that following diagnosis, physician visits declined, but within two to three years, that number rose to levels at or higher than those before diagnosis. The difficulty of diagnosis and the feelings of mistrust caused the women in this study to feel stigmatized by the medical community, which may contribute to an explanation for the decline of physician visits after a formal diagnosis is given. When Moira's rheumatologist told her to simply "Cheer up," she felt demeaned and misunderstood. These feelings caused her question the quality of care she was able to receive within the medical community and therefore seek help outside of this community. This finding is not uncommon and the stigmatization, which starts before diagnosis,

continues through the patients care afterward. Researchers Asbring and Narvanen (2002) found that women with FMS experienced stigmatization primarily before receiving a diagnosis and the vague symptomology FMS presents was a significant factor for causing the stigma. This stigma before diagnosis is caused by a medical practitioner who questions the veracity, morality, and accuracy of the patient's symptom descriptions. This phenomenon is clearly seen in the first theme when the women discuss their first symptom and the journey to diagnosis. From Brenda, whose doctor diagnosed her with postpartum depression after seeing her with her infant, to Kate, who struggled for five years to be correctly diagnosed, most of the women encountered stigmatizing discussions with their doctors. According to Asbring and Narvanen (2003), their participants coped with the stigma by either withdrawing from the medical community or finding new ways to approach the problem. The women in this study managed the stigma in very similar ways. Theme four discusses how the women started doing their own research on FMS and finding alternative ways of managing the symptoms.

This stigma and frustration may be exacerbated by miscommunication between the physician and patient. As earlier discussed, FMS is perceived by physicians as a difficult diagnosis to make. This is due to the disease's unclear etiology and pathogenesis, and many times requires doctors to make a subjective diagnosis (Ullrich, Hauer, & Farin, 2014). Additionally, many physicians see FMS patients as "interactionally difficult" (Asbring & Narvanen, 2003). Yet, for the FMS patient, communicating their symptoms in a way that can be easily understood is also a struggle. Choy et al., (2010) found that almost 60% of the patients with FMS admitted having

trouble discussing their symptoms to their doctors. This may be in part to the confusing nature of the symptoms and negative previous experiences in the medical community. Encounters between FMS patients and their health care providers are usually associated with the patient feeling disappointed, dissatisfied and rejected (Werner & Malterud, 2003). Therefore, it is important to understand the role communication plays in patient-provider relationships. FMS patients prefer an effective, open and patient-centered style of communication with their health care providers (Ullrich, et al., 2014). Additionally, they prefer an emotionally supportive style of communication from their doctors and nurses. Their results also showed that FMS patients have a great need for information from their providers and wanted not only to know information about their illness but also about other potential therapeutic alternatives and the pros and cons associated with each of these therapies.

FMS experience theme 3: Flares. The third theme reveals that participants all discussed how “flares” affected their lives. A flare is a sudden onset of symptoms that previously had been under control thanks to their prescriptions or activity level. Flares are not unique to FMS and can be seen as a common problem in many autoimmune disorders such as lupus and MS. Research often links flares with stressful situations. Brower (2009) found that commonly in flare research, studies employ experimental stressors, which include psychosocial, cognitive, exercise, and sensory/pain induction to evaluate physiological responses on the autonomic nervous system, the hypothalamic-pituitary-adrenal axis and the immune system. While physicians have clinically observed the flares, there has been very little research discussing the impact a flare has on the

individual and their relationships. One study indicates that patients most commonly identified stress as a main cause of flares (Vincent, Whipple & Rhudy, 2015). Other reasons included overdoing it, poor sleep, and weather changes. Additionally, they found that the common symptoms were flu-like symptoms, pain, fatigue, and decreased concentration. Finally, their participants coped with the flare by seeking treatments such as physical therapy or meditation, rest, avoidance, and patience. The present study found very similar discussions regarding the symptoms of a flare, the reasons, and the coping mechanisms used to both avoid and recover. Additionally, this research found that flares had a detrimental effect on communication between the patient and spouse. Because of the increased intensity of symptoms, the participants experienced more difficulty in motivation to communicate, as well as ability. During the interview, Jane discussed how her primary focus is isolation, as it helps her cope with the pain and fatigue. Yet, while this coping mechanism moderately helped with the illness, once the flare was over, they would experience feelings of guilt because they were not able to interact with their spouse and families, as they felt a need to retreat from their lives so that they could recover from a flare. While they were avoiding all stimulation, their husbands and children had to manage without them. The guilt that this tactic generates then serves to cause additional stress on the participants.

Guilt will be discussed in much greater depth when discussing RQ2's themes, but it is relevant here to note that this guilt was two-fold. First, the participants felt guilty for the inability to help with the daily chores and management of the household, which left their husbands to pick up the slack. The second is that due to the stigmatizing nature of

FMS, the participants felt pressure to validate their symptoms in hopes that their significant others would be more willing to help. While many of the women reported extremely positive relationships with their husbands, many still struggled at helping them understand how debilitating flares could be. What is unique to this population is the effect the stigma of the disease has on the participant. With other illnesses, concrete scientific testing can be ordered to find whether a patient has the disease or does not. FMS does not have a scientific test to confirm the diagnosis. As stated before, this causes the FMS patient to feel stigmatized because they cannot prove they are sick. In addition to an onslaught of negative symptoms such as debilitating fatigue and extreme musculoskeletal pain, the patient must also manage the believability perceived by those around them. This causes a cyclical problem as flares are caused by stress, and the illness itself can be extremely stressful on the patient and their relationships.

FMS experience theme 4: Coping strategies. The participants started doing their own research about FMS in order to manage their symptoms and cope with the illness. Similarly, Choy et al., (2010) found that over one third of patients they surveyed felt their illness was not well managed by their current treatment. FMS is not an easy illness to treat, which causes difficulty for both the patient and the provider. Matthias et al (2010) surveyed providers and found three themes: importance of the patient-provider relationship, difficulties when treating a chronic pain patient, and how treating a chronic pain patient would take an emotional toll on the provider. Physicians expressed frustration over the believability of patients' reports of pain and felt pressured to treat with opioids. Yet, when the women in the present study discussed coping methods in

dealing with their illness, most referenced natural treatment options highlighted by healthy methods such as diet changes and pain journaling. This separation in perspectives again shows the miscommunication that occurs between patient and provider when discussing FMS. This also shows that the use of open communication between the physician and the FMS patient is extremely important so that neither party makes incorrect assumptions of the others' motivations. Beiber et al., (2006) conducted an experimental study to understand the effects of a shared decision-making intervention on patient provider interaction, finding a significantly better quality of physician-patient interaction when using shared decision-making. Coping had more improvement in this group as well. Similar discussion was found in the turning point interview data. For some of the women, finding a physician who practiced open communication and shared decision-making had a strong impact on their illness. For example, Charlotte discussed how relieved she felt when she found a doctor who let her know she understood and wanted to find answers. Jane, too, remembered the positive impact finding a doctor who listened and helped her find answers.

Throughout the illness though, the participants found they needed to be their own advocate and started educating themselves not only about FMS, but also about ways to manage the illness. Some turned to dietary changes; others found support groups that were helpful; and almost all used the internet as an informational tool. This practice has been seen in FMS patients before. Asbring and Narvanen (2004) examined how FMS and chronic fatigue syndrome (CFS) patients sought control through acquiring knowledge about the illness. They sought knowledge through the internet, magazines, medical

journals, and textbooks. They also discussed their illness with acquaintances, health care providers, and patient support groups in order to find new information. Additionally, their information seeking changed throughout the course of the illness. In the beginning, the participants were looking for a diagnosis. After they received one formally through a doctor, they started seeking information on treatment options that would lead to an improvement or cure.

The findings in the study by Asbring and Narvanen are similar to the discussion during the turning point interviews. Three of the seven participants in this research discussed how they used resources outside of the medical community to not only diagnose themselves but to find alternate treatment options. Charlotte discussed using the internet to find a link between Lipitor© and FMS. When she did, she took this information to her doctors, who dismissed it. Yet, the information gave her the confidence to seek a doctor who would listen and validate her symptoms. Eventually because of using this coping mechanism, she found what she describes as an excellent doctor, who is one that listens to her needs and uses open communication to find therapies that have a positive impact on her illness.

The transactional model of stress and coping (Lazarus & Folkman, 1984) helps explain this phenomenon. This model states that when a stressful situation occurs, such as unexplained pain, an individual undergoes primary cognitive appraisal. In primary appraisal, a threat is appraised as irrelevant, benign, or stressful. In the case of FMS, the threat is most likely appraised as stressful as the patient is experiencing high degrees of pain, fatigue, brain fog, and other debilitating symptoms. At this point, the individual

undergoes secondary cognitive appraisal, assessing whether they have control over the outcomes, control over the emotions, or self-efficacy. The amount of threat the individual feels towards the stressor depends highly on the amount of control he/she has in the situation. If the individual has little control over the situation, such as with FMS, the threat causes him/her to enter two types of coping strategies, problem-focused or emotion-focused (Lazarus & Folkman, 1984). Problem-focused coping strategies attempt to manage the situation, whereas emotion-focused coping strategies attempt to manage the emotions felt due to the stressor. The transactional model of stress and coping focuses on the initial reaction to a stressor. The primary information-seeking behaviors can be categorized as a problem-focused approach to coping, which can be clearly seen in the turning point interviews. First, the patient searches for a solution to her symptoms. Diagnosis, however, does not end the search for a solution, as most were not satisfied with their treatment options. In the current turning point interviews, there was much discussion of times throughout the illness where participants tried different types of medication and lifestyle changes. At some point, the participants started focusing on emotion-focused strategies such as seeking social support.

While the women repeatedly discussed how thankful they were for their spouses, many also discussed searching outside the marriage to find social support. This usually entailed joining a support group (online or in person) or seeking therapy. Previous researchers have found a link between loneliness and FMS. Kool and Greenen (2011) found when comparing FMS, RA, ankylosing spondylitis and osteoarthritis, patients with FMS experienced significantly more loneliness than the other rheumatic diseases.

Additionally, they found that both a lack of social support and feelings of invalidation due to the nature of their illness were correlated with loneliness. It is extremely important for providers and caretakers to promote social support as a method to cope with FMS. One method in this research that many of the women discussed was the use of online social support groups. They were able to share information and have a place to turn when looking for advice. This is typical of online support group experiences as discussed in previous literature. Chen (2012) found themes of information-sharing regarding both prescription treatment options as well as alternative therapies such as exercise, diet and other lifestyle changes, in addition to sharing experiences and coping strategies. Van Uden-Kraan et al., (2008) found similar outcomes of online social support groups. Their participants reported empowering outcomes such as being better informed, feeling more confident with their physician, treatment and social environment, improved acceptance of the disease, increased optimism, and enhanced self-esteem.

RQ2: Turning points in the barriers from and needs for social support. The second turning point graph asked the women to focus on a significant relationship and discuss how their communication changed throughout the lifetime of their FMS.

Social support theme 1: Guilt. The first theme in this turning point graph for five of the women was feelings of guilt. Similarly, Arnold et al., (2008) discovered that due to the irregularity of the symptoms, FMS patients had difficulties performing even mundane tasks such as cooking for the household. The turning point analysis demonstrates that guilt or shame results from rearranging priorities due to FMS. For example, guilt stems from feeling FMS made them selfish and forced them to focus on only their own needs

and not those of their children or husbands. Equity theory may help us understand these feelings of guilt (Deutsch, 1985). This theory focuses on how individuals perceive whether the sharing of resources is fair to both relational partners. These resources may be things like money, time, and energy. Equity is then measured on the perceived ratio of contributions to benefits and how they compare between partners. While the ratios do not have to always be equal between the partners, the partner that contributes more should also receive more benefits in order for the relationship to remain equitable. In an inequitable relationship, one partner is over-benefited and the other is under-benefited (Walster, Walster, & Bercheid, 1978). This inequity leads to feelings of stress for both partners. The over-benefited partner feels guilt whereas the under-benefited partner feels angry at being taken for granted. Over time these feelings may lead to finding ways to restore equity, adjusting the way the partners view the relationship, or exiting the relationship altogether.

The participants in this study felt that they were over-benefited and their husbands were under-benefited. They discussed how their husbands would have to take on both sets of responsibilities in order to keep the house running. For example, Kate discussed how her husband “does it all.” He would cook and shop for the family’s needs and, in her opinion, would be the person her children could go to if they needed anything. She felt distress because while she wanted to be that person, her FMS would not allow her to be; she felt guilty because her husband had to do everything. Moira summed it up when she said she felt her husband had been cheated out of an “equal partner.” This guilt would also affect their communication in two ways. Some of the women discussed keeping their

symptoms private as to not worry their spouse, but others discussed how the inequity in the relationship would cause them to bottle up their emotions out of worry. Kate was worried her husband would think she was too selfish if she discussed her FMS too much and that it would cause resentment.

Because of this guilt, the participants were constantly looking for ways to find equity in their relationship. According to Walster et al. (1978), there are three ways to balance the equity in a relationship: restore actual equity, adjust psychological equity, and leave the relationship. Throughout the interviews, the participants discussed ways in which they had tried to restore equity in their relationship, but because of their FMS, the options were limited. They could not take on more of the chores or help more with the children on a consistent basis due to their illness, but tried to help as best they could, whenever they could. They also coped with the perceived inequity by choosing to rely on their spouse for only instrumental support and not emotional support. While this will be discussed more in theme three, this may actually lead to more inequity in the relationship due to partner resentment if he does not fully understand why he is taking on more responsibilities. While some FMS symptoms are constant, many fluctuate and relational partners need to know when the symptoms have gotten worse, so they understand how to help. Without this communication, resentment is more likely to grow. The second option, according to Walster et al. (1978) would be to adjust their psychological equity. While this is usually performed by the person who is under-benefited, the participants discussed using this tactic as well. When the women would question why their husbands stayed in the relationship even though they were doing the majority of the work, they would

reassure themselves that they had more to offer their partner than doing the chores. This would translate into discussions of how the couple was a good match and that there were times where they would remember having fun and just simply enjoying each other's company. These monologues helped them to see that the relationship was not completely unequal and gave them reassurances that they were not as bad a partner as they felt. The final option would be to leave the relationship (Walster et al., 1978). For the participants in this study, this was not an option. Regardless of the guilt the participants knew they were extremely dependent on their husbands. Kate said it best. "I am so lucky to have a husband who takes excellent care of me. He does so much for my children and me. He does all the chores, drives me and the kids wherever we need to go and is a wonderful care-taker. This man even washes, dries, and arranges my hair, when my daughter isn't doing it!"

Social support theme 2: Loneliness. The second theme discussed by the participants was feeling alone due to their FMS. All of the patients discussed how their illness was extremely isolating. One major reason they felt isolated was due to the way the disease affected their lives. FMS symptoms are extremely uncertain. The participants may feel relatively well one day, and the next have a major flare which would cause them to be confined to a bed. This made it very difficult for the participants to make plans. Arnold et al., (2008) had similar findings when discussing the impact of FMS with patients. They reported participants were reluctant to commit to social activities but also felt pressured to attend because they did not want to seem unreliable. Additionally, as in this research, many of the participants had to quit their jobs because of FMS and the

debilitating symptoms. This took away another avenue for support that had previously been in their lives and negatively affected their identity.

Because all of the participants in this study lost friends and co-workers due to their illness, they felt very alone. This loneliness has a negative impact on the physical nature of the disease which in turn causes detrimental communication practices. Wolf, Davis, Yeung and Tennen (2015) found that lonely episodes were associated with subsequent increases in negative thinking patterns regarding pain, which in turn would increase pain within a day. In even healthy individuals, loneliness can be linked with poor health. A study by Segrin and Domschke (2011) demonstrates a link between loneliness and less functional recuperative processes, specifically sleep and leisure. This can have a strong impact on FMS patients as their sleep is already disrupted due to the illness. Many FMS patients report insomnia and trouble staying asleep due to pain and stiffness. Loneliness may have a large impact on their insomnia and can also affect how they process their pain (Wolf, et al., 2015). When their pain or loneliness increased, the participants in this study were less likely to seek out communicative support with their spouses, thereby increasing their loneliness and pain.

Another possible cause of their loneliness is the invisible nature of the disease, which causes questions of authenticity. The participants in this study reported times when they were frustrated because those close to them could not fully understand the illness. Their husbands sometimes forget the sporadic nature of the symptoms and assume they can do something when they cannot. Almost all said at one point that others just did not “get it,” meaning outsiders were unable to fully understand their experiences. Because of

this, the participants would not self-disclose to their friends and family because it was too hard to explain. This is a common problem for the FMS community (Barker, 2005; Mengshoel & Heggen, 2004; Thorne et al, 2004; Wolfe, 2009). Through this research we can start to see a link between FMS, communication, and loneliness. One possible explanation would be that as the patient experiences more debilitating FMS symptoms, communication is reduced due to either the fatigue from the disease or the frustration of trying to be understood, or both, which then increases loneliness. Another possible explanation would be that as communication lessens in general, loneliness occurs and FMS symptoms become worse. More research needs to be performed to better understand how these three variables (communication, loneliness, and FMS symptoms) interact. Future research might focus on the type of communication occurring between the FMS patient and their communicative partner. For example, if the patient is using more closed communication during interactions with others, she may not be able to receive the support they need and may feel lonelier. She may switch to closed communication out of these feelings of illness authenticity.

Many of the participants felt lonely that even in places where they should easily find support, such as a FMS support groups. It may be that they still felt they were not completely understood. This may be due to the wide range of experiences and symptoms seen in this population. Dennis, Larkin, and Derbyshire (2013) discovered a similar pattern; rather being a homogeneous group, people with FMS vary widely in their experiences. This variance even amongst themselves may create issues for patients participating in support groups and hoping to find similarities rather than

differences. This may impact the level of support actually found, as well. For example, an emotional or social coping mechanism for one individual may not work for another. Also, because the disease experience lies on a spectrum of mildly affected to extremely debilitating, support group members may experience feelings of jealousy or even place themselves on a hierarchy where those with the worst symptoms, or vice versa, dominate the communication in the support group. Finally, as seen in the analysis for RQ1, patients with FMS cope with the illness by trying to find methods to control their symptoms, whether through research or experimentation. These coping methods are highly individualized to each patient's symptoms, and what helps one person may not help another. This may lead to frustration that causes members to question the helpfulness of a support group.

Social support theme 3: Instrumental support. The third theme revolved around the descriptions of the social support received by the participants. They overwhelmingly discussed receiving instrumental support from their husbands throughout their FMS experience. According to Willis (1991), there are four common functions of social support: emotional, instrumental, informational and companionship. Emotional support can be classified as the offering of sympathy, concern, affection or love. Instrumental support can be classified as tangible ways in which people assist others. Informational support involves giving guidance, advice or useful information, and companionship support involves giving someone a sense of belonging.

Emotional support would appear to be one of the most important types of social support this population needs and is indeed extremely beneficial to FMS patients in the

doctor/patient relationship (Ullrich et al, 2014), yet it was the least discussed in the turning point analysis. The previous findings discussed participants' feelings of guilt and loneliness and illuminated how these feelings affected communication between the FMS patient and the spouse. For example, many of the participants expressed not wanting to talk about their problems with their spouses because they did not want them to worry. They already felt guilty because they were not able to physically help by performing household duties, so they did not want to place more stress on their partner by discussing their illness as well. Therefore, if there is a lack of communication of something such as worsening symptoms, spouses may not know the FMS patient needs emotional support (i.e. to give sympathy or show concern). This lack of emotional support then impacts the loneliness felt by the participants. When they do not receive sympathy or concern, they may start to feel that they are alone in battling the disease. Another aspect important to understanding helpful types of social support is how emotional support is conceptualized for the participants.

One reason the women remember instrumental support as being particularly helpful is due to the nature of FMS. Because this illness causes symptoms such as fatigue, brain fog, and wide-spread pain, the participants cannot perform the same tasks they once could. Also, because each participant in the sample had children and domestic responsibilities, a major concern was to make sure the home ran smoothly for the children. This included chores such as cooking, cleaning, and supervising. By providing the instrumental support in these areas, the husbands were not only able to help them tangibly but also emotionally as their worries regarding the household were alleviated. In

some situations instrumental support can also be interpreted as emotional support because it shows caring, understanding, and affection to the person receiving the tangible help. However, rarely is emotional support translated as instrumental support (Semmer et al., 2008). This is important to the FMS population when taking into consideration their symptoms and needs. While emotional support is important, instrumental support reduces stress on the FMS patient because they have fewer responsibilities that may be difficult for them to accomplish. This is important because as previously stated there is a clear link between stress and symptom flares (Brower et al., 2010; Vincent, Whipple, & Rhudy, 2015). As research has demonstrated, when a FMS patient is under more stress, they are also more likely to have a flare. It is conceivable then that the most helpful type of support overall would be instrumental as it reduces stress in a very tangible way. The participants did not have to worry about the housework and instead could focus on finding ways to feel better.

Additionally, according to Semmer et al. (2008), the manner in which the support is given is an important link as well. If someone begrudgingly helps, it sends a different message to the person receiving support, rather than if someone helps with no complaints. Yet, what may be more important to this study is the perception surrounding the social support. The interviews revealed the participants had extremely positive feelings about the instrumental support their husbands were able to give. While some did mention times their husbands were a hindrance rather than helpful, for the most part they viewed the support they received as a positive interaction. Throughout the interviews the participants only mentioned a select few times when their husbands were unhelpful; the

rest of the time they would give their spouse a glowing review. However, the view they had of themselves was markedly different. Many of the participants discussed frustration at the fact that they could no longer perform the same duties and tasks that they could before they got sick. Because they saw this change in needs as a direct result from the illness, they placed the blame on their illness and by proxy, themselves, rather than on something their husbands did or did not do. Because of these changes, the participants would feel an overwhelming sense of guilt. Due to the change in ability, and the strain it has on their lives and marriages, many were just glad their husbands did not leave them. For example Angela said, “Whenever I ask myself why he sticks with me through this [FMS], I just remind myself that he wakes up next to me every morning and goes to sleep next to me every night.”

Another dimension of social support that was discussed in the turning point graphs was positive social interactions. This dimension involves the availability of other persons to do fun things with the subject. While FMS does hamper the participants to do most physically stressful activities, many still found enjoyment despite the disease. One key coping mechanism was to find low stress/low impact hobbies. When their husbands would join in on this hobby they felt strong support. For example, Jane’s husband joined her in a warrior dash and afterward became actively involved in finding more races. This shared hobby allowed her to feel closer to her husband and helped them connect in an aspect separate from FMS. Not all women were able to run obstacle races, but many talked about a time when their husbands would join them in an activity, or even a new

diet regimen. This support helped the women to feel less lonely and helped them feel more connected to their spouse.

RQ3: Turning point comparisons. Overall there were few commonalities between the turning point events in the illness experience and the turning point events with the relational other. The main reason is likely the lack of day-to-day open communication about the disease. However, it must be noted that this analysis was very micro-level. Commonalities across the two turning point analyses are likely to be found in the broader context and nuances. The participants repeatedly discussed themes of guilt and loneliness, and these two factors had a major impact on their communication. As previously discussed, the FMS patients felt guilty because they thought they were not an adequate relational partner for their husbands. Jane stated, “I don't want the guilt of not being a good enough wife,” when discussing her frustrations with FMS. These feelings primarily happened at the beginning of the disease or during a flare because that was when they would be forced to depend heavily on their spouse. Therefore, because they have strong feelings of guilt they would use privacy management to reduce the amount of stress they placed on their husbands. They decided to keep secrets regarding symptoms and the severity so that they were not a larger burden.

Communication privacy management (CPM) theory is therefore a fruitful source of insight into these findings. CPM explains how individuals maintain privacy by setting up boundary structures that help them regulate the risks inherent in disclosing private information (Petronio, 1991, 2002). These boundary structures are based on two fundamentals associated with private information. First, people believe they own

information about themselves and should have the right to control who had access to that information. Second, people believe they can decide how freely they will allow others to share the information that they disclose. CPM also has three principles that influence the rules placed on boundaries. First, boundaries are influenced by five main factors: culture, personality, the relationship, biological sex, and motivations. Second, boundary management often requires involving others in the secret thereby making them co-owners of the information. Finally, co-owners sometimes undergo boundary turbulence. CPM also discusses types of family secrets: whole family, intra-family, and individual. Whole family secrets are held by the entire family. Intra-family secrets are held by only a few of the family members, and individual secrets are held by a single individual. The turning point graphs were focused on the individual and their experiences. Therefore, we can label the secrets discussed in the data as individual secrets.

Applying CPM principles to the turning point interview data, the two factors that may have a large impact on disclosure are the relationship and their motivations. The relationship factor would seem to predict that we tend to disclose more to individuals we care for than with those we dislike. The analysis, however, revealed that the participants reversed this factor. It is clear that each participant actually chose to refrain from seeking emotional support from her spouse precisely because she cares for him. For example, Kate discussed not wanting to worry her husband more by telling him her symptoms were worsening. The second factor, motivation, might lead to a conclusion that people who worry about getting hurt or rejected will avoid self-disclosure that could make them vulnerable. The data analysis, however, reveals that the primary motivation for the

participants was to not place more stress on their partner. Because she feels over-benefited, the participant does not want to exacerbate inequity by asking for emotional support on top of the instrumental support they already receive. Further, because the instrumental support is more important to retain familial status quo, the participant relinquishes emotional support in favor of instrumental support.

Yet, the nature of the relationship in light of the FMS required their husbands have some knowledge, thereby casting them as co-owners of information about the FMS experience. This co-ownership in itself allows for the patient to move between times of thin boundaries, where she may disclose much information about the illness, to times of thick boundaries, where she may disclose little. Because the spouse knows his wife has a chronic illness, he may no longer question symptom changes, which allows the wife to constantly choose what to share and what to keep private. Due to the unpredictability of FMS symptoms, these women experience frequent boundary turbulence. According to Petronio (2002), boundary turbulence occurs when new events call for renewed boundary management and smooth management of co-owned information requires coordinated actions. Boundary turbulence can be caused by incongruent expectations, misunderstanding privacy parameters, or conflicted access rules for handling private information. When a dyad discovers that preset privacy rules are not working, they will recalibrate the rules to fit their needs (Petronio, 2002). FMS patient may recalibrate boundaries to reduce guilt. For example, changes in symptoms and the ways they manage them require the participants to navigate whether to disclose the information and how. Overall, participants chose to keep much of the day-to-day information about their illness

private from their spouses and therefore used topic avoidance and secret-keeping. Their motivations for this were both relationship-based and information-based. As stated previously, many of the participants discussed keeping secrets or avoiding topics so as to not place more stress on their spouse. Under CPM, this motivation can be classified as relationship protection (Petronio, 2002). The data reveal that they are enacting topic avoidance in order to maintain the equity balance previously established. The participants felt that placing more burdens on their spouse would result in further inequity, giving them stronger feelings of guilt. To reduce guilt, they avoided the topic, keeping their symptomology changes a secret for as long as possible. Yet, this strategy simply leads to more problems; another theme found in the data was loneliness. The participants reported feelings of loneliness because they thought those around them were not able to understand the FMS experience. However, keeping information secret denies their spouses the opportunity to better understand. This creates a relational impasse that is detrimental to both the illness and relational experiences.

Another motivation for topic avoidance and secret-keeping is information-based. They may feel that further discussion of symptoms and the illness is futile. As previously discussed, it is normal for an FMS patient to experience symptoms for an average of five years before formal diagnosis. When discussing the first turning point (first symptom), many of the participants mentioned conversations they had with their partner. These conversations usually revolved around the unexplained pain, fatigue and cognitive impairments as they were the symptoms that had the most impact. As time went on, though, the conversations about the symptoms were reduced. Perhaps participants found

that discussing the problem was not helpful. In light of their motivation to reduce their husbands' stress, it is reasonable to conclude that topic-avoidance and secret-keeping are ways of concentrating on communication that is perceived as helpful, even though there are undesirable consequences, which they may or may not foresee. One consequence is that it harms the spousal relationship through lower quality of interaction. Secret keeping in romantic relationships is associated with lower relational well-being (Ursal, Lin, Knee & Bush, 2012), and topic avoidance is negatively related to relationship satisfaction (Dailey & Palomares, 2004). While lack of validation and empathetic communication from the spouse may exacerbate secret-keeping and avoidance, he is hampered in his ability to validate and empathize in the first place because of that avoidance. Still, the turning point analyses revealed that overall the women were satisfied in their relationships. This seeming discrepancy between theory and the findings is explained by the overwhelming guilt and associated thankfulness felt by the participants. Because the women were so thankful for the instrumental support they already received from their spouses, they still felt satisfaction with the relationship even though they were keeping secrets and experiencing the negative consequences of that. The party more affected by the secret-keeping and topic avoidance may actually be the spouse of a patient with FMS. More research is warranted to better understand the relational effect of FMS from the spousal perspective.

Relational communication competence improvements through counseling based in this research may have promise to prevent the impasse caused by secret-keeping. In the interview phase of the study, one patient rarely discussed keeping secrets from her

spouse. In this particular relationship, she and her husband were extremely open in their communication with each other. Throughout the relational turning point graph, she discussed how her husband was the driving force in getting her to self-disclose about her feelings and emotions regarding the day to day FMS experience. One variable that was different in this relationship as well was that their 18 year old son was regularly willing to pick up the chores that she could not accomplish, and her husband did not have time to accomplish. This additional caregiver may help alleviate both the actual and perceived stress placed on the husband which in turn creates a more open avenue for requesting emotional support. Finally, she discussed how her husband encouraged her to find other individuals to help when he felt he could not. For example, he encouraged her to join pain management classes through their HMO and to use social media to connect with other FMS patients. This case highlights the need for communication based counseling to help couples find individual tools to help open the avenues for emotional support. As each family has different variables that may make communication easier or more difficult, and individual treatment plan needs to be implemented for long-term success.

Relationships outside the family unit are also negatively impacted by secret-keeping and topic avoidance. Five of the women discussed losing friendships because they felt they could not talk about FMS with their friends. For example, Jane stated, “I sometimes want my friends to simply go away because they are of no use anyhow. They aren't there when I need it, and they rarely understand what I'm going through.” Brenda had a similar experience: “I get asked consistantly why I don't participate with friends when they do anything athletic.” Because they were unable to communicate about their

FMS and because they could not participate in the same activities as before, many found that as time passed, their friends moved on. This had a great impact on their loneliness and caused them to be even more dependent on their spouses. This may also have an impact on their perception of how satisfied they are with their spousal relationship versus their friend relationships. If their friends all leave them when they are sick, their husbands look even more pleasing in their eyes because they are now acting out of the norm in a positive way.

Another negative but more individualized consequence of secret-keeping is higher levels of depression, stress, and agitation. Ursal et al. (2012) suggest this may be due to the constant monitoring and suppression of thoughts or feelings that are being kept secret. This stress may then lead to cause a flare, which leads to more secrecy, and so on in a downward spiral. Additionally, research illustrates a link between topic avoidance and depression. Greater levels of topic avoidance are associated with higher levels of anxiety and depression among breast cancer patients. Topic avoidance decreases patients' use of emotional support and increases patients' self-blame which leads to physiological distress (Donovan-Kicken & Caughlin, 2011). The turning point analysis revealed similar findings. The participants discussed fewer instances of emotional than instrumental support, feeling they were at fault for much of the stress on the family unit. Finally, keeping information secret may change the person's perception thereby rating the secret more negatively than they did originally. Derlega, Metts, Petronio, and Margulis (1993) found that the perception of the secret may change over time. In this study, the longer the participant went without disclosing issues about FMS, the more stress was placed on their

bodies, manifesting in a symptom flare. Even though the women knew stress played a large role in their illness trajectory, they still felt unable to ask for emotional support. The participants coped with this problem in various ways. Some tried to find an overall balance so that there would be nothing to disclose as their symptoms were mild to moderate; others looked for external help through doctors or medicine. Finally, one participant found that talking to herself in the car helped ease the stress of keeping her secret. Yet, none of these avenues of coping involve communicating with their spouse about their illness. This finding highlights the magnitude of guilt felt by the participants. They are willing to find any means necessary to cope with their illness that will not place more responsibility on their spouse and increase inequity.

RQ4: Predicting social support. After analyzing the turning point data (Phase 1), preliminary themes informed the survey questionnaire (Phase 2). Overall, the questionnaire focused on variables involving perceived communication competence of both self and other, communication behaviors, relational measures such as happiness and self-disclosure, social support and coping. In many of the items, the survey responses were similar to the qualitative data in phase one. For example, to validate the interview findings, one item asked which type of social support they received and from whom in their life they received it. When asked who gave them the most emotional support, slightly less than half of the participants reported their spouse. Yet, when asked who gave them the most instrumental support, almost 80% identified their spouse as the most helpful. This validates conclusions from the interviews, in which many of the women discussed how thankful they were for their husbands' help around the house and with the

children, yet only infrequently mentioned how their husbands helped them emotionally. When emotional support was mentioned, it was not as positive. Regarding emotional support, 30% of the participants stated their friends helped them the most. This is different from the qualitative data in which many of the women discussed how they lost friendships. This difference may have resulted simply from the types of questions asked in the interview protocol. As the interviews focused on a singular relationship, the participant did not have much opportunity to discuss outside friendships. Future research should focus on friendships and FMS to understand the emotional support received.

One last finding from this item was that when asked who helped them the most overall, 72% again stated their spouse. This is only a 7% drop from the instrumental support question, reinforcing the conclusion from the qualitative study that the most helpful type of support is instrumental. This finding regarding instrumental social support is extremely insightful for health researchers who seek to understand the communication needs of FMS patients. . With that said, however, loneliness remains an issue that may be related to the lack of emotional support. More research should be performed to better understand how FMS patients can find emotional support either within or outside of a primary relationship.

The fourth research question, analyzed quantitatively, queried the role of communication and relational satisfaction in predicting social support. Through a stepwise multiple regression analysis, perceived communication competence of the spouse and overall satisfaction with the relationship were highly significant predictors ($p < .000$) and positively predict social support ($\text{adj. } R^2 = .77$). This finding suggests that

when a participant perceives their spouse as a competent communicator and they are satisfied with the relationship overall, they report higher levels of social support from that person. This finding diverges from previous research in FMS and social support. For example, Kool and Greenen (2012) found that patients with FMS were lonely due to a lack of social support. The data shows that the participants feel comfortable asking for support when they feel their relationship is satisfying and their partner is a competent communicator. It may be that Kool and Greenan's assumption of directionality is faulty and that loneliness and social support are both predicted by spouse's communication competence and relational satisfaction.

The finding from RQ4 also diverges slightly from the relational health communication competence model (RHCC, Kreps, 1988). RHCC posits that the level of communication competence shown by important participants in how the care is delivered, directly relates to the individual's ability to make cooperative health care relationships, share relevant information, make informed health care decisions and coordinate activities such as health education and social support. While the model was originally derived from the health care delivery system wheel (Kreps & Thornton, 1984) which focused on the complexities of the patient/provider relationship, the RHCC has focused on interpersonal relationships. Query and Kreps (1996) focused on the relationships between caregivers and Alzheimer's patients, examining the relationship between communication competence, social support and cognitive depression and found that caregivers who perceived themselves a highly competent communicator, had larger social networks and higher levels of support satisfaction. This model gives the results in this study a broader

understanding. Unfortunately, research on the RHCC model had focused primarily on the communication competence of the patient. The competence of other in the relational system has been neglected empirically. The present research suggests that an important predictor to social support was the perceived communication competence of the spouse/caregiver and may further explain the link between practitioners, patients, and spousal support. Future research should examine communication competence of all parties in the system (i.e. the patient, lay caregivers, and medical practitioners).

Previous studies regarding the RHCC have found that the more communicatively competent the patient, the better the health outcomes regarding social support, overall satisfaction, information exchange and cooperation. The findings from this study reveal though, that the perception of their partner's communication competence is more important than their own. There may be a myriad of reasons, but one may stem from the difficulty with illness authenticity. FMS patients may feel that because their illness is invisible, how the information will be received is more important than being competent at sharing the information. This perception may start within the healthcare continuum and transfer to their interpersonal relationships. Because researchers have found there is both an inherent difficulty in finding a diagnosis and a communication break-down between many doctors and patients, the patient may feel it is the receiver who is incompetent, rather than themselves, which causes them to reduce their open communication with their practitioners. This experience may cause a change the perceptions of all receivers. As the practitioner is originally seen as an authority on medical topics, if they are not able to understand and help, the patient may assume laypersons cannot understand as well, and

this conclusion may cause FMS patients to reduce their communication about the illness with all relational partners. This finding may help to explain why FMS patients usually report smaller social networks and lower levels of information exchange. If they feel the receiver is not communicatively competent enough to understand their experience, they will be less likely to discuss that experience. These explanations may allow health researchers to better understand why social support is not found in certain settings. If a relationship is not satisfying, the participant may feel too vulnerable asking for social support. Additionally, if they feel their partner is not a competent communicator, they may feel that it would be too difficult, even futile, to ask for help. The RHCC model would suggest that when the patients' communication competence is reduced by the physical and emotional stress of her illness, others in the relational system should be obligated to compensate for her compromised competency by improving their own. Applications of this work might provide protocols for counseling that achieves this result.

Another notable finding from this multiple regression is that the variable of communication competence of self was not a significant predictor. Previous research on FMS has focused on the difficulty patients have in communicating due to both cognitive disparities caused by the illness as well as stigma. Lyons et al. (2013) found that when patients reported more communication problems than their spouse, the spouse thought the pain was less than the FMS patient was experiencing. Also when the spouse reported more communication problems than the FMS patient, the spouse thought the pain was worse than the patient was experiencing. This highlights the problems inherent in relationships where one partner has FMS. Because pain cannot be seen by the spouse,

they must guess whether the communication problems they perceive are due to worsening pain. Whereas, the patient perceives communication worsening as a result of the spouse's lack of understanding. Lyons et al. (2013) lends understanding to this finding. If the patient's perception of the spouse's communication predicts social support, it may be that her motivation to seek support is affected. Communication competence of the patient seems to be unimportant in finding support from their spouse.

Another reason this variable was not a significant predictor of social support may be related to CPM. The consideration of privacy management may help us understand the miscommunication discussed in the turning point analysis. When the participants discussed their loneliness, they stated they felt their spouse would not understand them, or it would cause them to focus on the negative and make them feel worse. This would lead the participants to keep secrets and/or avoid discussions of FMS all together. The only time they would discuss their FMS was when needing instrumental support. When asking for emotional support, the emphasis is on the patient, yet when asking for instrumental support the emphasis is on the spouse. When the women would ask for advice or for their spouse to listen, communication competence of self would be highly important. It would help them explain their illness so that they could be understood. Yet when asking for a tangible favor such as doing the dishes, the perceived competence of the spouse may be seen as the more important variable. It is relatively easy to ask for help if you think the person you are asking will be willing to help.

RQ5: Coping. The final research question focused on whether coping is predicted by communication competence of self, perceived communication competence of spouse,

relational satisfaction and social support. The results of the stepwise multiple regression were not significant for any variable other than communication competence of self ($p < .000$; $R^2 = .08$), which only explains a very small amount of the variance. There may be two reasons for these findings. The first major reason may lie in the measurement of coping. The coping variable was measured through one question which asked “How has your coping changed in the last six months.” This question is unlike the predictor scales in that it measures changes in coping, while the scales were focused on present communication competence, relational satisfaction and social support. In future research, the question should focus on current coping mechanisms used by the participants and should focus on the different types of coping they use such as support from their spouse, performing research, or changes in lifestyle. A second reason might be that for the participants, coping is conceptualized differently. Throughout the turning point analysis, when the participants discussed coping, they mostly referred to informational coping methods such as trying new medications. The research question was focused more on emotional coping such as discussing their illness and seeking emotional support from their spouse.

Therefore in order to better understand coping in this sample, a third stepwise multiple regression was performed which added two additional independent variables from the survey that had not been used in the original analysis (FMS symptom change over last six months and relationship satisfaction change over last six months). This multiple regression found that all three independent variables predict coping changes. This analysis shows that illness changes, communication competence and relationship

changes predict 37% of the variance of changes in coping. The results of this multiple regression analysis are summarized in the table below.

Table 5.1: Predictors to Coping 2

| Step | Predictor | R ² ch | β |
|------|--|-------------------|------|
| 1. | Illness change over 6 months | .304*** | .510 |
| 2. | Communication Competence of self | .038*** | .186 |
| 3. | Relational Satisfaction change over 6 months | .014*** | .137 |
| | R ² | .369 | |

Note. N=150. *p <.05, **p <.01, ***p <.001

Table 5.2: Bivariate Correlations of Independent Variables with Coping 2

| | Coping | Illness Change | Relational Satisfaction Change | Competence of Self |
|--------------------------------|--------|----------------|--------------------------------|--------------------|
| Coping | | | | |
| Illness Change | .56** | | | |
| Relational Satisfaction Change | .22** | .12 | | |
| Competence of Self | .30** | .18* | .18* | |

Note. N=150. *p <.05, **p <.01, ***p <.001

This regression analysis shows that the largest predictor of coping is the change in illness which echoes the findings from the turning point graphs. When the women discussed coping, they did so in an individualized manner. They felt that the things that helped them cope the most were researching and finding ways to manage their FMS, rather than emotional or instrumental support. Coping methods varied: finding pain management trials, making dietary changes, and finding a balance between living their life and

adjusting to FMS. While their husbands were important, they were not the primary focus. As discussed earlier, the participants felt the mostly needed instrumental support from their partner so that they could focus on their individually-based coping strategies. For example, Kate discussed a time when her husband managed the Fourth of July festivities and children so that she could relax and not over stress her body. This in turn created less stress for her as she was not worried about causing a flare the next day. This researcher would hypothesize that to the participants, positive shifts in their illness helps them feel like they are coping better because they most likely feel that this way of managing the symptoms is the correct method for their bodies, whereas social support does not have as immediate effect on the symptomology of FMS. It may be that coping is defined by physical illness trajectory rather than social or emotional factors.

Theoretical Implications

This research was able to further equity theory, CPM, and RHCC through the use of a sequential exploratory method. The qualitative data illuminated the turning points in not only their communication with a relational other but also their turning points with FMS. Further, the quantitative data largely supported the themes found qualitatively. After thorough analysis, a model of communication within this population can be hypothesized. This model is shown in the figure below:

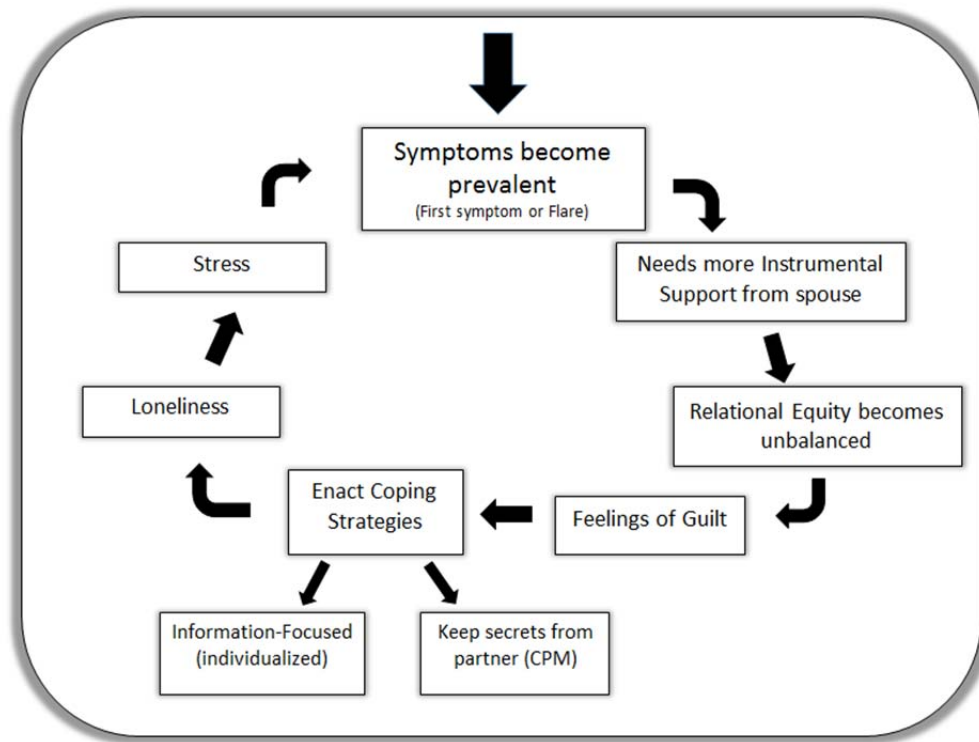


Figure 1: Model of Communication in FMS patients

The model begins with the participant experiencing symptoms. This stage can start with either the first symptoms experienced or with a significant flare as either will move the participants to the next stage, instrumental support. Because the symptoms create difficulty for the participant to perform even daily household chores, they had to rely on their spouse to do them. This then would engender a change in the relationship. Where previously the relationship was considered equitable, the need for instrumental support created new inequity. According to equity theory, the participants became over-benefited while their spouse became under-benefited. This change led to significant

feelings of guilt that motivated the participants to find coping strategies. Unfortunately, because they already felt over-benefited, they would resort to individual-based strategies such as researching cures alone or enacting communication privacy by keeping feelings and new symptoms secret so to not cause more unbalance in the relationship. Because they performed these coping methods alone, they started to feel lonely and from there had two options: turn to their spouse for emotional support or internalize these feelings and create stress. If they turned to their spouse or others for emotional support, they effectively exit the model, whereas if they create more stress for themselves due to this internalization they then would cause a flare of symptoms, thereby restarting the model. Finally, the FMS patient re-enters the model whenever a flare takes place. This model furthers the discipline's understanding of both equity theory and communication privacy management theory as researchers now can see that the equity outcome may lead to enactment of thicker privacy boundaries and more individualized secret-keeping and/or topic avoidance. Additionally, this research adds to the body of knowledge on RHCC by expanding consideration of communication competence to the social network and to perceived competence of others. Future research might further examine the roles that relational partners' communication competence and the perceived communication competence of others may have in the healthcare process.

Practical Implications

One of the more important implications in this study is that guilt is an extremely strong mediating factor to open communication for this population. Additionally, guilt conceptually bridges the gap between equity theory and communication privacy

management theory. Due to the inequity of duties and instrumental support in a FMS relationship, the women feel strong levels of guilt as they are over-benefited and their spouse is under-benefited. This then leads them to keep individual secrets from their spouses and to avoid the topic of FMS so as not to place more responsibility on the spouses' shoulders and further increase the inequity. This finding is important because practitioners, such as physicians and counselors, can target these issues in the relationship and help the couple mediate the guilt and subsequent stress it causes. Researchers and practitioners may be able to enact programs to help FMS patients manage their feelings of guilt in a more productive way. For example, seminars could focus on ways to help FMS patients find equity in their relationships that buffers the perception of inequity created by the instrumental support they require, which would help diminish guilt. One option may be for practitioners to recommend family support groups or simply couple support groups. Tamar, Roccoforte, Hseih, Cook and Pickett, (1997) suggest a family support group is one way the entire family can find help. This solution may be able to help the couple find strategies together to manage the inequities felt in the relationship and find techniques approved by each person to restore a more equitable balance. Due to the findings regarding secret keeping and topic avoidance, it can be hypothesized that the participants do not feel comfortable or do not know how to start the discussion of inequity and guilt, and therefore an outside party may be able to mediate and help them communicate in a more open manner. If that is not an option, then mental health practitioners need to at least better understand the role equity, guilt and privacy

management has on the patient and possibly find individual strategies to help the patient cope with her guilt.

Another practical outcome of this study is the discussion of coping mechanisms and online information-seeking regarding their FMS. The participants in phase one discussed using the internet to help them find ways to manage their illness. These included finding online support groups, getting access to pain management trials, researching medication options, finding dietary changes, or ways to find balance between their lives and the illness. This finding is particularly important as it gives researchers an understanding of how to reach FMS patients. Because it was so difficult for most to be diagnosed, they sometimes turned to the internet before they turned to a practitioner. This medium can bridge the gap between health care practitioners and FMS patients. Access to information about the full effects of FMS and the ways it may affect the patient's life may help the user find coping mechanisms and information to reduce stress rather than increase it. Ziguras (2000) found that the internet provides patients with the ability to shop for medical advice, review literature about treatment plans, discuss health-related issues with other disease sufferers and that it boosts feelings of empowerment regarding their diagnosis and treatment. Yet, the use of the internet as a primary coping mechanism may be problematic for two reasons. Coping appears from this study to be a highly individualized process. Because they did not feel they could turn to their partners or physicians for informational support, they individually found ways to manage the illness and symptoms on their own. This is challenging for multiple reasons. First, Fox and Rainie (2002) found that one in five patients use information obtained online as a

replacement for expert medical advice. Due to the frustration associated with being diagnosed, some were able to diagnose themselves before a physician and only went to a doctor to get confirmation. Secondly, this finding is problematic because it diminishes the social support from their relational partner. If the FMS patient is turning to the internet to find coping mechanisms, they may not discuss the strategies fully with their partner which may cause communication or relational problems later on. More FMS resources need to emphasize the importance of social support and the importance of discussing the online research with someone in the patient's life. If the relational partner is more aware, the couple can decide together what steps to take and how to manage the day-to-day difficulties that accompany FMS.

Limitations of the Study

Phase 1. While extensive efforts were made to keep limitations to a minimum, some did emerge. One limitation was the sample size in phase one of the study. Despite contacting over 100 people diagnosed with FMS, only seven were able to complete the turning point graphs and interview. Many of the people contacted reported they were simply not well enough to discuss their illness for almost an hour. Others stated they were too overwhelmed by the turning point graphs and asked to leave the study. Another limitation to this phase of the study was similar demographics of the participants. Almost all held a bachelor's degree or higher. Additionally, all of the participants were married with children and for six of the seven, the children were living in the home. These factors may have accounted for themes to emerge which may not be present in a more diverse sample.

Phase 2. Unfortunately, this phase of the study had limitations as well. Due to the variables under investigation, multicollinearity was an issue. Multicollinearity is a phenomenon where two or more predictor variables are highly correlated. This can have an effect on the findings as the coefficient estimates may change unreliably due to small changes in the data and may cause the coefficients to be estimated with higher standard errors which leads to greater uncertainty. In order to account for multicollinearity, a stepwise multiple regression was chosen so that the researcher could better identify the changes in the model. However, it is impossible to determine the nature of the relationships among variables due to their high intercorrelation. Due to multicollinearity, this research cannot make judgments on whether the variables are simply independent variables, mediator variables, or moderator variables. Mediating and moderating variables clarify the relationship between the independent variable and the dependent variable. A mediational model hypothesizes that an independent variable influences a mediating variable, which then influences the dependent variable. A moderating variable indicates when or under what conditions a particular outcome can be expected. Unfortunately because the independent variables were so highly intercorrelated, there is no way to hypothesize how the variables, relational satisfaction and communication competence affect social support in RQ4 and the variables relational satisfaction, communication competence, and social support affect coping in RQ5.

Another limitation to this phase of the study was also due to sample demographics. While gender was accounted for due to the nature of the study, the vast majority of the sample identified as Caucasian/White (91%). This may have skewed the

findings due of issues such as racial/ethnic disparities within the health care community, cultural communication differences and the digital divide. In 2007, African Americans had an overall death rate that was 30% higher than Caucasians (Williams, 2013). Additionally Geronimus et al., (2006) found that early health deterioration of black adults was evident across multiple biological systems. FMS affects men and women from many different racial backgrounds, yet in both the literature and in this study as well, African American women have not been accessed for research. Race/ethnic disparities within the health care system and cultural differences in communication may play a large role in the understanding of FMS and communication; therefore in future studies, a more purposive sample needs to be obtained.

Future Research

From this research, a few new avenues have arisen. First, future research needs to focus on both the patient and the spouse to get a better understanding of the communication barriers to social support. In this research, it was discovered that guilt has a large role in the lack of emotional support seeking behaviors. What is not understood, though, is whether this is perceived by the partner and ways in which the partner has tried to mitigate this problem. Additionally, more research needs to be performed to understand the effects inequity has on the spouse who is under-benefited. While a study by Bigatti and Cronan (2002) found that spouses report more depression symptoms, more loneliness, and stress than healthy couples, the communication changes between the couple due to FMS has yet to be examined. Another avenue of research that needs to be examined in more depth is how FMS affects relationships outside of the marriage dyad.

Previous researchers have found that FMS patients have a difficult time maintaining friendships (Asbring & Navanen, 2003; Choy et al., 2010), yet when asked during the questionnaire regarding social support, there was a difference between seeking support from their spouses to splitting the emotional support between their spouse and a friend. This finding highlights the need for a better understanding of the changes in friendships and communication due to FMS. If some FMS patients are able to maintain at least one friendship, there may also be a strategy for helping other FMS patients to do the same. More research needs to be performed though to better understand this phenomenon.

Also, as previously discussed, FMS affects men and women of all races and ethnicities, yet previous researchers primarily examined FMS using a Caucasian sample. More research needs to be performed to understand if and how communication about social support and coping changes due to race, ethnicity and sex. Communication researchers have long held the understanding that different cultures communicate differently. For example, some cultures are more willing to self-disclose than others. It is because of this that more research needs to be performed to understand how women of different ethnicities, who have been diagnosed with FMS, communicate about their illness with their spouse. Also, historically, FMS has been seen as an illness that affects primarily women, yet as it has gained more understanding, men are being diagnosed with it more frequently. Therefore, FMS needs to be studied in this population as well. What are the prevalent themes regarding communication and social support for men diagnosed with FMS and how does this compare to the communication practices of women? Additionally, because FMS has attained more attention from both the medical community

and the US community at large, the prevalence is changing, and the NIH currently states that FMS may affect 20% of men. As discussed earlier, invisible illness is largely affected by gender. Many studies on FMS have discussed the difficulty associated with getting a diagnosis (Choy et al., 2010; Perrot et al., 2012, Werner, et al., 2004). One of the reasons it is so difficult to acquire a diagnosis is due to gender and a historical bias that women are more prone to “hysterics” than men, and therefore the pain they feel must be more psychological than physiological. This gender bias would not be present for men when seeking medical help with FMS, and because of this, more research needs to be performed to better understand the communication between patient and provider in this situation. Additionally, there exists a gender stereotype in the US that women are weaker and therefore more likely to complain about pain. This preconceived notion may also play a role for men who are seeking a diagnosis. Finally, as seen in men with PTSD, seeking help for stigmatizing illnesses is not easy, and this too may affect not only patient-provider interaction but also the patient and their interpersonal relationships. Understanding the differences in experiences may help researchers understand the difficulties for women as well, as we would be able to pinpoint the areas of similarity and difference.

One last area that needs to be further explored is the effect of the coping mechanisms used by FMS patients on their experience and their communication. This research found that the women primarily coped with their illness by trying to find ways to reduce the symptoms. Largely this coping mechanism was used only by the FMS patient and was not always discussed with the spouse. Similar to Lazarus and Folkman’s (1986)

discussion of emotion, information, and perception-focused coping, the participants in this study were largely found to utilize information-focused coping mechanisms. This greatly impacted their social support. Because they used an individualized form of coping, they did not utilize a relational form through emotional-coping. They thought if they could control the symptoms, they would have no need for emotion-focus coping and emotional social support. Unfortunately this one coping mechanism was rarely enough to manage their illness and their feelings regarding their illness. More research needs to be performed to better understand how this population can utilize other forms of coping in order to better manage their illness. This present research took steps in this direction by illuminating a key reason the participants did not reach out for emotional support and thereby did not use emotion-focus coping. Yet, experimental studies may be better able to find ways for the FMS patient to mitigate their guilt and use more varied forms of coping. Certain relational scripts may help the patients find a way to ask for emotional help.

Conclusion

The researcher intended to understand how communication affects social support and coping for individuals with FMS, and the research questions were derived from previous research on chronic illness and the first phase of the study. As a result of her own experience with Lyme disease and CFS, the researcher gained insights on how those with FMS may seek social support and subsequently find coping strategies. While her experience was bracketed during the data analysis, it was an instrumental tool when communicating with the participants. Because the researcher had a similar personal understanding of their experiences, the participants reported they found it easier to

communicate with the researcher. Additionally, because there was a shared understanding, the subjects felt more motivated to participate in the research, as they felt it would be a safe space to discuss their experiences. During the data analysis, great care was taken so that the findings were informed by the data rather than the researcher's bias, which can be seen through the rich data provided by the participants.

Overall, this study found that instrumental social support was a prevalent theme in both the qualitative and quantitative phases. Yet, the other types of support (emotional and informational) were not utilized as much. This may be due to the changes in the equity of the relationship. When the participant developed FMS, they were forced to rely more on their spouse for instrumental support, and due to the unpredictable nature of FMS, the participants were constantly in need of this support. The sudden change in responsibilities resulted in a shift in equity and forced the participant to become over-benefited and the partner to become under-benefited. This change led to significant feelings of guilt that affected support-seeking behaviors. Because they felt they were too much of a burden in regards to instrumental support, they felt they could not ask for more support in a different form and chose instead to enact individual coping strategies. These strategies included information focused-coping techniques and secret-keeping or topic avoidance with their spouse. Rarely, these coping methods worked and the participant could work towards building equity in the relationship again. Usually, however, the use of individual coping techniques engendered loneliness which led to more stress. Finally, past researchers have discovered that stress, either physiological or psychological has a large impact on FMS and leads to worsening symptoms or "flares."

This research extends the body of knowledge regarding equity theory, communication privacy management theory, and the relational health communication competence model and creates further avenues of study for future research. Practically, this research helps practitioners understand the impact communication has on FMS patients and may help to identify ways to combat negative behaviors.

APPENDIX A

Bracketed Experience

This research is driven by my own struggle with chronic pain that occurred due to Lyme disease. One summer, I sprained my ankle due to a fall. Yet, this was not a normal sprain. It continued to ache and swell long after the normal two-week healing period. Because I could not walk on it without pain, a month after the incident I decided to see a sports medicine doctor, who prescribed x-rays, physical therapy and an orthopedic boot. However, the x-rays found nothing, and he assured me I would be fine after a month in the boot. After a month passed with no answers and constant pain that was now in my other foot, knees and hips, I decided to see a podiatrist to find more answers. She prescribed an MRI, which discovered I had badly bruised three bones in my foot. At this point, I was instructed to spend another month in the boot and we would re-evaluate in another month. As the time continued I was still in constant pain and not healing, at which time my doctor prescribed a bone scan to see if there were stress fractures in the foot. The bone scan showed massive arthritis in both feet and two stress fractures in my right foot. As I was only 25 at the time, I was left with more questions than answers.

During these first six months of treatment, I felt like I was going insane. I knew I was in pain, but my doctors could never find a definitive reason for the amount of pain I was in. I could tell that by going into every appointment saying “I am still hurting,” they

would look at me like that was not the response they were expecting to the question of “How are you feeling today?” At one point, my doctors even diagnosed me with compound regional pain syndrome in efforts to explain the pain, which later I was told I did not have.

Also in the first six months, the pain affected my interpersonal relationships. I withdrew from activities because it was harder to get around and stand for long periods of time. While everyone could see that I was injured, I found that for most of my friends did not change their plans for me, instead they seemed surprised that I could not attend. Over time, I started to notice that I was receiving fewer invitations to get-togethers. When I asked a friend why I wasn’t invited, she replied, “oh well everyone figured you would say no.” I also noticed over time that people would stop asking me how I was feeling or would only partially pay attention to the answer I gave. This was probably because they knew that nothing had changed, and I was not feeling well. I also learned to dislike any questions about how I was feeling because my answer never changed and I felt awkward always saying the same response of telling them I was hurting. So I started to just lie and say the pain was getting better because that gave me a nicer response from my friends and colleagues. This, however, hindered my ability to receive social support and had ramifications for receiving support later because my friends would think I was fine, and I would confuse them or make them think I was not telling the truth if suddenly I wasn’t feeling well.

The pain also affected my attitude in that I was rarely in good moods and made sleeping difficult because I was never able to find a comfortable position where I was not

in some form of pain. This too affected my relationships both in my personal life and at work. Because I was never in a good mood, my colleagues didn't want to hang out with a "Negative Nancy," as I was told by one work friend. Also my personal friends were tired of my down mood and they too withdrew. This greatly hurt my ability to find social support.

As time continued, I eventually I stopped wearing the boot because it was damaging my hips and back. Because the leg in the boot was longer than my other leg in a shoe, it made my hips disproportionate which caused more pain. Eventually, my doctor also found nerve damage my feet due to the time spent in the orthopedic boot and prescribed Lyrica, a medicine used for fibromyalgia to treat nerve pain. While the medicine worked well, it also caused me to gain 20 pounds in a month, which prompted me to stop taking it. I figured the extra weight would only make the arthritis pain worse, so I would rather deal with the nerve pain. The result of taking off the boot, though, made my pain all the more invisible. Now it was very easy for my friends and work colleagues to forget that I wasn't completely well. This affected my relationships in that most people wouldn't understand why I was in a bad mood, or why I needed help getting something from the copy room because they could not see that I was still injured.

After four doctors and six months of constant pain in my feet, knees, hips and back, I asked for blood work to be done to rule out lupus and RA. The doctor also decided to test me for Lyme disease. In about two weeks, my results were in; I had Lyme disease and had probably been bitten by a deer tick well over two years ago. After I knew that I had an explanation for the pain and fatigue, I felt less crazy, but the diagnosis did

not stop the symptoms. Eventually, my Lyme disease specialist also diagnosed me with chronic pain syndrome caused by the Lyme.

Being diagnosed with Lyme disease caused me to have more trouble finding social support. Because the disease was completely invisible to the naked eye, it was my choice to tell people I was ill. When I first found out, I only told my family, my bosses, and two friends. Eventually though I recognized the need for more support than just those individuals could give me, and I slowly opened up about my illness with the rest of my friends as well as my work colleagues. Yet, I encountered two problems when I disclosed my illness. The first was that most people had heard of Lyme disease, but they didn't know the symptoms, which forced me to explain how the disease affected my body. At times, I enjoyed educating others about my disease, but at others it was exhausting because I would not have the energy to explain it to them. The second effect this had on my ability to find social support was that while I told people about my illness, because I looked well, many would forget I was ill, and I would be placed in an awkward situation where I would have to remind them. I personally always felt awkward in this situation for two reasons: I felt I was putting them in a situation where they would have a negative face because they forgot about something as important to me as my illness, and it also brought to attention the fact that I was sick.

While I was never directly diagnosed with fibromyalgia, I was diagnosed with chronic pain and my own diagnosis is very similar in the symptoms and the stigmatization of fibromyalgia. For a long time I felt like a hypochondriac because while I knew I was hurting, no medical provider could find a definitive reason. It is because of

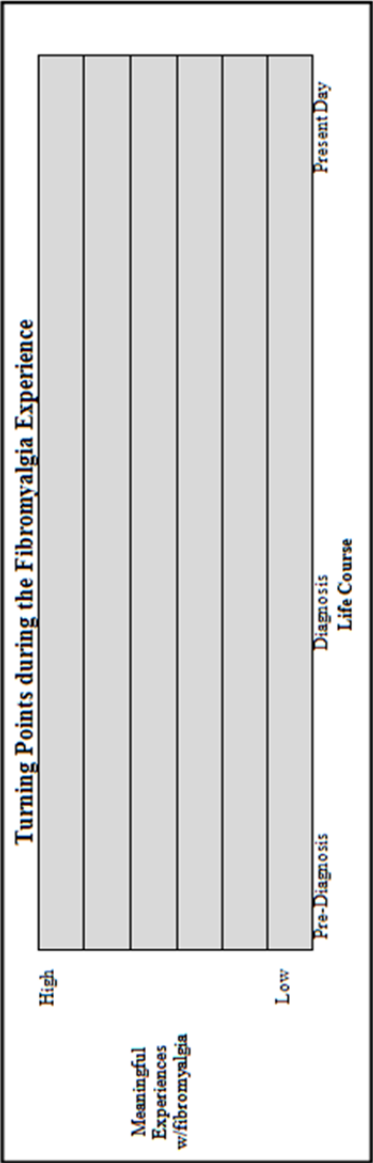
my experience with chronic pain that I want to discover the barriers patients with fibromyalgia have in finding and receiving social support.

The literature on social support in a health context is clear: social support improves health outcomes (Cornman et al, 2003; Achat, et al, 1998). For example, literature shows that people who have fibromyalgia and have support are less likely to be depressed and use less painkillers, than those who have support who are more likely to participate in healthy behaviors such as light exercise to help the pain (Ursal & Lu, 2011). I seek to understand not only how fibromyalgia patients seek support, but also what keeps them from receiving the types of support they need.

APPENDIX B

Turning Point Handouts

Turning points with the Disease



INSTRUCTIONS:

There are no right or wrong answers. Everyone who completes this graph has their own specific representation of their experiences with fibromyalgia.

Please use this graph to represent turning points you have experienced as they relate to fibromyalgia. Turning points are moments when you recall changes in meaningful experiences. Meaningful experiences are any point in the course of fibromyalgia where something significant occurred with the disease. This graph is a chance for you to reflect on your experiences and take some time to recall them. We will use this graph to guide us during part of the interview.

Recall the time before you were diagnosed. Please draw a dot above the label "pre-diagnosis" to indicate your meaningful experiences with the disease at this time. "Low Meaningful Experiences" means you had negative meaningful experiences with the disease at that time, and "High Meaningful Experiences" means you had positive meaningful experiences with the disease. For example, if you were experiencing very few problematic symptoms, you would put a dot close to the "high meaningful experiences" on the graph. If you were experiencing many problematic symptoms, you would put a dot close to the "low meaningful experiences." For each dot, please write one word or a brief phrase above the dot that best describes this experience for you. Next, please make a dot above the label "Diagnosis" to represent the meaningful experience of being diagnosed. Next, indicate your meaningful experience with fibromyalgia for today.

Now I'd like you to make any dots on the graph when the experiences you had with fibromyalgia changed. You can add dots anywhere they pertain along the life course of the disease. You may recall changes in experiences due to a specific event (e.g. new medication) or it may not be in reference to a specific event (e.g. you just recall a change in your attitude to the disease or symptoms). Again, please write a brief phrase of what the turning point was at that time (e.g., "horrible side effects"). Once you have placed all of the experience changes along the line, connect the dots that you plotted with a line.

Turning Points with a Relational Other

Turning Points during the Fibromyalgia Experience

| Meaningful Experiences w/Relational Other | Pre-Diagnosis | Diagnosis Life Course | Present Day |
|---|---------------|-----------------------|-------------|
| High | | | |
| | | | |
| | | | |
| | | | |
| Low | | | |

INSTRUCTIONS:

For this worksheet you will plot turning points you experienced with a relational other. Your relational other is a person who has had an impact on your fibromyalgia experience and could be a spouse, a friend, a coworker, or a family member.

Recall the period before you were diagnosed. Please draw a dot above the label "pre-diagnosis" to indicate your meaningful experiences with your relational other at this time. "Low Meaningful Experiences" means you had negative meaningful experiences with this person at that time, and "High Meaningful Experiences" means you had positive meaningful experiences with this person. For example, if the communication or interaction with your relational other was not helpful for you, you would put a dot close to the "low meaningful experiences" on the graph. If the communication or interaction with your relational other was very helpful for you, you would put a dot close to the "high meaningful experiences." For each dot, please write one word or a brief phrase above the dot to note this. Next, please make a dot above the label "Diagnosis" to represent any meaningful conversations with your relational other at this time. Next, indicate your meaningful experiences them today.

Now I'd like you to make any dots on the graph when the experiences you had your relational other have changed. You can add dots anywhere they pertain along the life course of the disease. You may recall changes in experiences due to a specific event (e.g. a conflict) or it may not be in reference to a specific event (e.g. you just them being supportive). Again, please write a brief phrase of what the turning point was at that time (e.g., "listened to me"). Once you have placed all of the experience changes along the line, connect the dots that you plotted with a line.

APPENDIX C

Interview Protocol

Date of Interview: _____

Location: _____

Time Began: _____

Time Completed: _____

Introduction and Purpose of Interview

I am conducting this interview as a part of my dissertation project for a PhD in Communication at George Mason University. I am interested in learning more about social support and the fibromyalgia experience.

You have volunteered for participation in this project as a person who has been diagnosed with fibromyalgia syndrome, is that correct? Are you also over the age of 18? With your permission, I would like to record this interview and take brief notes as well; is that okay?

Please remember that you do not have to answer any question(s) that you are not comfortable answering and you can stop this interview at any time if you so choose. Also, please know that all information shared in this interview is confidential and cannot be traced back to you. In fact, pseudonyms will be used in any papers written for the dissertation. Do you have any questions or concerns?

Ok so let's start discussing the experiences you plotted on your graph from the point in time before you were diagnosed and up until the present day. Please tell me as much information as you can recall about each experience or event. Again, providing as much detail as possible, and within your comfort level, in each of your responses will be the most helpful to me.

Line #1: Questions and probes to use throughout

PROBES

EXPLAIN – (re: perceived meaning)

EXAMPLE – (specific experience)

ELABORATE – (more detail)

EXTEND – (timeline—what happened before)

1. What changed in your life as a result of this turning point?"

Probe: what effects did this TP have on your job/relationships/emotions?

2. How did you cope with this turning point?"

Probe: Was this way of coping helpful? How do you know? (Change in feelings, behavior?)

Probe: Where did you turn for support at this TP?

3. How would you describe your well-being during this turning point?"

Probe: Physical/emotional/spiritual/ relational?

Probe: Is this different from other events or experiences you have had to cope with?

4. How would you describe your communication during this turning point?"

Probe: What did you talk about? What was not talked about?

Probe: Who did you talk to? Who did you not talk to?

Probe: Where did these discussions occur? (Physical or spatial location)

Probe: Why did you communicate about FMS when you did?

Next Point... Go through all points in same manner

Line #2: Questions and Probes for Use throughout Interview:

5. How would you describe your communication with your primary relational partner at the time of this turning point?

Probe: What did you talk about? What was not talked about?

Probe: did you avoid any topics? Why/Why not?

Probe: Where did these discussions occur? (Physical or spatial location)

Probe: Why did you communicate about FMS when you did?

6. How did your relationship change during this turning point?"

Probe: How did your closeness change?

Probe: How did your frequency of talk change?

Probe: How did your time spent together change?

7. How would you describe your well-being during this turning point?"

Probe: relational

8. Looking back, what type of supportive behavior did you need from your relational partner during this turning point?"

Probe: Why?

Probe: Can you think of an example?

9. How was the support you received helpful/unhelpful?"

Probe: What behavior was most helpful?

Probe: What behavior was least helpful?

Next Point... Go through all points in same manner

I always end by giving you a chance to discuss anything in your experience as a woman with fibromyalgia—how fibromyalgia has affected you, your relational other, and your bond that you think are important to recognize or consider.

Questionnaire for Fibromyalgia Patient

1. Please note your age

AGE _____

2. Please note your ethnicity.

Caucasian _____ African-American _____ Asian _____

Native American _____ Hispanic _____ Other _____

3. Please note what level of education you have completed.

Some high school _____ High school graduate _____ Some college _____

Associate's degree _____ Bachelor's degree _____ Some graduate work _____

Graduate degree _____

4. Please note your work status.

Don't work _____ Work part-time (20 hrs/week) _____

Work full-time (40+hrs/week) _____ Full-time student/Don't work _____

Full-time student/Work part-time (20 hrs/week) _____

Full-time student/Work full-time (40+hrs/week) _____

5. Please note your total household annual income.

\$0-\$20,000 _____ \$21,000-\$30,000 _____ \$31,000-\$40,000 _____

\$41,000-\$50,000 _____ \$51,000-\$60,000 _____ \$61,000-\$70,000 _____

\$71,000-\$80,000 _____ \$81,000-\$90,000 _____ \$91,000-\$100,000 _____

over \$100,000 _____

6. Please note your marital status.

Single _____ In long-term relationship _____ Engaged _____

Married _____ Separated _____ Divorced _____

Divorced/Re-married _____ Widowed _____ Widowed/Re-married _____

7. Please list your current place of residence: City/State _____

APPENDIX D

Mixed Methods Part 2: Fibromyalgia and Communication Questionnaire

1. For these questions please indicate how strongly you agree or disagree with the statements.

I am comfortable in social situations
My loved ones can tell when I'm happy or sad
My loved ones truly believe that I care about them
I can put myself in others' shoes
My conversations are characterized by smooth shifts from one topic to the next
I accomplish my communication goals
My communication is usually descriptive not evaluative
My conversations are usually one sided
I allow my loved ones to see who I really am
When I have been wronged, I confront the person who wronged me.

2. When you are looking for verbal support (i.e. listening, offering advice, understanding, etc.) regarding your fibromyalgia, who do you usually turn to?

| | | | |
|-------------------|--------|---------|-------|
| Significant other | Parent | Sibling | Child |
| Best Friend | Other | | |

3. When you are looking for support in the form of physical help (i.e. running errands, doing chores, driving, going with you to doctors' visits, etc.) regarding your fibromyalgia who do you usually turn to?

| | | | |
|-------------------|--------|---------|-------|
| Significant other | Parent | Sibling | Child |
| Best Friend | Other | | |

4. Who has helped you the most in managing your fibromyalgia?

| | | | |
|-------------------|--------|---------|-------|
| Significant other | Parent | Sibling | Child |
| Best Friend | Other | | |

5. On average how often do you and your spouse discuss your fibromyalgia in some way:

Once a month
Once every two weeks
Once every week
Several times a week
Once a day
Several times a day

6. Listed below are statements regarding how you feel about your communication and your spouse. Please indicate how strongly you agree or disagree by choosing the corresponding number.

1. Strongly Agree 2. Agree 3. Neither agree or disagree 4. Disagree
5. Strongly Disagree

He or she says several things that seem out of place in the conversation

Overall I find our conversations are very useful and helpful

He or she is an ineffective conversationalist

He or she has said some things that should not have been said

Overall I feel rewarded in the conversation

Everything he or she says is appropriate

I obtain my goals in the conversation

Overall I have useless conversations with this person

Some of the things he or she has said are embarrassing to me

Our communication is very proper

Overall our conversations are unprofitable for me.

I get what I want out of the conversation

At least one of his or her remarks have been rude.

He or she is a smooth conversationalist

I find our conversations very unrewarding overall

He or she is effective at communicating with me.

Our conversation is suitable to the situation

I achieve what I want to achieve in the conversation

Our conversations are unsuccessful

The things he or she talks about are in good taste, as far as I'm concerned.

7. Listed below are statements regarding how you feel about your fibromyalgia and your spouse. Please indicate how often they interact with you and these issues.

1. None of the time 2. A little of the time 3. Some of the time 4. Most of the time

5. All of the time

I get together with my spouse for relaxation

My spouse is someone whose advice I really want

My spouse would help me if I were confined to a bed

My Spouse gives me good advice about a crisis

My spouse takes you to the doctor if you needed it

My spouse shows me love and affection

My spouse would prepare your meals if you are unable to do it yourself

My spouse helps you with your daily chores if you could not do them.

My spouse is someone I can have a good time with

You can turn to your spouse for suggestions on how to deal with your fibromyalgia

My spouse is someone I can do things with to help me get my mind off things

My spouse is someone I can count on to listen to me when I need to talk

My spouse gives me information to help with your fibromyalgia
 My spouse understands my problems
 My spouse makes me feel loved and wanted
 My spouse hugs me
 My spouse is someone I can confide in or talk to about myself or my problems
 I share my most private worries and fears with my spouse
 I do something enjoyable with my spouse

8. Check the dot on the scale line below which best describes the degree of happiness, everything considered, of your present marriage. The middle point, "happy," represents the degree of happiness which most people get from marriage, and the scale gradually ranges on one side to those few who are very unhappy in marriage, and on the other, to those few who experience extreme joy or felicity in marriage

Very Unhappy . . Happy . . Perfectly Happy

9. State the approximate extent of agreement or disagreement between you and your spouse on the following items.

1. Always Agree 2. Almost Always Agree 3. Occasionally Disagree
 4 Almost Always Disagree 5 Always Disagree

Handling Family Finances
 Matters or recreation
 Demonstration of Affection
 Friends
 Sex Relations
 Conventionality (right, good or proper conduct)
 Philosophy of life
 Ways of dealing with in-laws

10. When disagreements arise, they usually result in:

Husband giving in
 Wife giving in
 Agreement by mutual give and take

11. Do you and your mate engage in outside interests together?

All of them
 Some of them
 Very few of them
 None of them

12. When thinking about how you spend your leisure time:

To be on the go To stay at home

Do you generally prefer

Does your spouse generally prefer

13. Do you every wish you had not married?
 Frequently
 Occasionally
 Rarely
 Never
14. If you had your life to live over, do you think you would:
 Marry the same person
 Marry a different person
 Not marry at all
15. Do you confide in your spouse?
 Almost never
 Rarely
 In some things
 In everything
16. How satisfied are you with this relationship?
 Very satisfied satisfied neither satisfied or dissatisfied dissatisfied very dissatisfied
17. In the past 6 months what has happened to your level of satisfaction with this relationship?
 Very satisfied satisfied neither satisfied or dissatisfied dissatisfied very dissatisfied
18. What is your age: _____
19. What is your ethnicity:
 Caucasian African-American Asian
 Hispanic Native American Other
20. What level of education have you completed:
 Some high school High School Graduate Some college
 Associate's degree Bachelor's degree Some graduate work
 Graduate degree
21. What is your work status:
 Don't Work Work part-time (20 hr/week) Work full-time (40+ hrs/week)
 Full time student/ Don't work Full-time student/Work part-time(20 hrs/week)
 Full-time student/Work full-time (40+ hrs/week)
22. What is your total household annual income
 \$0-\$20,000 \$21,000-\$30,000 \$31,000-\$40,000 \$41,000-\$50,000
 \$51,000-\$60,000 \$61,000-\$70,000 \$71,000-\$80,000 \$81,000-\$90,000
 \$91,000-\$100,000 over \$100,000

23. What is your marital status:

| | | | |
|-----------|---------------------------|---------|-------------------|
| Single | In long-term relationship | Engaged | Married |
| Separated | | | |
| Divorced | Divorced/Remarried | Widowed | Widowed/Remarried |

24. What is your state of residence. _____

25. When were you diagnosed with Fibromyalgia?

| | | | |
|-------------------|----------------|---------------|-------------|
| Over 10 years ago | 10-8 years ago | 8-6 years ago | |
| 6-4 years ago | 4-2 years ago | 2-1 years ago | less than a |
| year ago | | | |

26. In the past 6 months what has happened to your fibromyalgia?

| | | |
|------------------------|---------------------|---------------------|
| Significantly improved | Moderately Improved | Mildly improved |
| Stayed the same | Mildly declined | Moderately declined |
| Significantly declined | | |

27. In the past 6 months how do you feel you are coping with your fibromyalgia?

| | | |
|---------------------|----------------------------|-------------------------|
| Coping has improved | Coping has stayed the same | Coping has gotten worse |
|---------------------|----------------------------|-------------------------|

REFERENCES

- Aaron, L. A., Bradley, L. A., Alarcón, G. S., Alexander, R. W., Triana-Alexander, M., Martin, M. Y., & Alberts, K. R. (1996). Psychiatric diagnoses in patients with fibromyalgia are related to health care-seeking behavior rather than to illness. *Arthritis & Rheumatism*, 39, 436-445.
- Achat, H., Kawachi, I., Levine, S., Berkey, C., Coakley, E., & Conditz, G. (1998). Social networks, stress and health related quality of life. *Quality of Life Research*, 7, 735-750.
- Afifi, T., Caughlin, J., & Afifi, W. (2007). The dark side (and light side) of avoidance and secrets. In B. H. Spitzberg, & W. R. Cupach (Eds.), *The dark side of interpersonal communication (2nd ed.)*. (pp. 61-92) Mahwah, NJ: Erlbaum.
- Aghabeigi, B., Feinmann, C., & Harris, M. (1992). Prevalence of post-traumatic stress disorder in patients with chronic idiopathic facial pain. *British Journal of Oral Maxillofacial Surgery*, 30, 360-364.
- Agne, R.R., Thompson, T.L., & Cusella, L.P. (2009). Stigma in the line of face: Self-disclosure of patients' HIV status to health care providers. *Journal of Applied Communication Research*, 28, 235-261.
- Albrecht, T. L., & Goldsmith, D. J. (2003). Social support, social networks, and health. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of Health Communication*. Mahwah, NJ: Erlbaum.
- Amir, M., Kaplan, Z., Neumann, L., Sharabani, R., Shani, N., & Buskila, D. (1997). Posttraumatic stress disorder, tenderness and fibromyalgia. *Journal of Psychosomatic Research*, 42, 607-613.
- Arnold, L. (2008). Management of fibromyalgia and comorbid psychiatric disorders. *The Journal of Clinical Psychiatry*, 69, 14-19.
- Arnold, L.M., Crofford, L.J., Messe, P.J., Burgess, S.M., Palmer, S.C., Albetz, L., & Martin, S.A. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counseling*, 73, 114-120.

- Asbring, P. & Narvanen, A.L. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, 12, 148-159.
- Asbring, P. & Narvanen, A. (2003). Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science Medicine*, 57, 711-720.
- Asbring, P. & Narvanen, A.L. (2004). Patient power and control: A study of women with uncertain illness trajectories. *Qualitative Health Research*, 14, 226-240.
- Avtgis, T. A. (2003). Male sibling social and emotional support as a function of attributional confidence. *Communication Research Reports*, 20, 341-347.
- Bair, M. J., Robinson, R. L., Katon, W., & Kroenke, K. (2003). Depression and pain comorbidity: a literature review. *Archives of internal medicine*, 163, 2433-2445.
- Barge, K. & Musambira, G. (1992). Turning points in chair-faculty relationships. *Journal of Applied Communication Research*, 20, 54-77.
- Barling, J., MacEwen, K. E., & Pratt, L. I. (1988). Manipulating the type and source of social support: An experimental investigation. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, 20, 140-153.
- Barker, K. (2005). *The Fibromyalgia Story: Medical Authority and Women's World of Pain*. Philadelphia, PA: Temple University Press.
- Baxter, L. & Bullis, C. (1986). Turning points in developing romantic relationships. *Human Communication Research*, 12, 469-493. DOI: 10.1111/j.1468-2958.1986.tb00088.x
- Baxter, L. A., & Montgomery, B. M. (1996). *Relating: Dialogues and dialectics*. Guilford Press.
- Bediako, S. M., & Friend, R. (2004). Illness-specific and general perceptions of social relationships in adjustment to rheumatoid arthritis: The role of interpersonal expectations. *Annals of Behavioral Medicine*, 28(3), 203-210.
- Beehr, T. A. (1995). *Basic organizational psychology*. New York: Allyn & Bacon.
- Beiber, C., Muller, K., Blumenstiel, K., Schneider, A., Richter, A., Wilke, S., Marnmann, M., & Wolfgang, E. (2006). Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia: A qualitative and quantitative 1 year follow-up of a randomized controlled trial. *Patient Education and Counseling*, 63, 357-366.

- Bennett, R. M., Jones, J., Turk, D. C., Russell, I. J., & Matallana, L. (2007). An internet survey of 2,596 people with fibromyalgia. *BMC Musculoskeletal Disorders*, 8, 27.
- Bennett, S., Perkins, S., Lane, K., Deer, M., Brater, D & Murray, M. (2001). Social support and health related quality of life in chronic heart failure patients. *Quality of Life Research*, 10, 671-682.
- Berg, C. A., Wiebe, D. J., Butner, J., Bloor, L., Bradstreet, C., Upchurch, R., Hayes, J., Stephenson, R., Nail, L. & Patton, G. (2008). Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychology and Aging*, 23, 505-516.
- Berkman, L. F. (1995). The role of social relations in health promotion. *Psychosomatic medicine*, 57, 245-254.
- Bernard, A., Prince, A., & Edsall, P. (2000). Quality of life issues for fibromyalgia patients. *Arthritis Care Research*, 13, 42-50.
- Bigatti, S. & Cronan, T. (2002). An examination of the physical health, health care use, and psychological well-being of spouses of people with fibromyalgia syndrome. *Health Psychology*, 21, 157-166. DOI:10.1037/0278-6133.21.2.157
- Bolton, C. D. (1961). Mate selection as the development of a relationship. *Marriage and Family Living*, 23, 234-240. doi:10.2307/346967
- Bloom, J. R., & Kessler, L. (1994). Emotional support following cancer: A test of the stigma and social activity hypotheses. *Journal of Health and Social Behavior*, 35, 118-133.
- Braithwaite, D. O. (1990). From majority to minority: An analysis of cultural change from able-bodied to disabled. *International Journal of Intercultural Relations*, 14, 465-483.
- Brock, R.L., & Lawrence, E. (2009). Too much of a good thing: Underprovision versus overprovision of partner support. *Journal of Family Psychology*, 23, 181-192.
- Brower, R. G. (2009). Consequences of bed rest. *Critical care medicine*, 37, S422-S428.
- Brummett, B. H., Babyak, M. A., Barefoot, J. C., Bosworth, H. B., Clapp-Channing, N. E., Siegler, I. C., ... & Mark, D. B. (1998). Social support and hostility as predictors of depressive symptoms in cardiac patients one month after hospitalization: a prospective study. *Psychosomatic Medicine*, 60, 707-713.
- Bullis, C. & Bach, B. (1989). Socialization turning points: An examination of change in organizational identification. *Western Journal of Speech Communication*, 53, 273-286.

- Bullis, C., Clark, C., & Sline, R. (1993). From passion to commitment: turning points in romantic relationships. In P. Kalbfleisch (Ed.), *Interpersonal communication: evolving interpersonal relationships* (pp. 213–236). Hillsdale, NJ: Erlbaum.
- Burckhardt, C. S., Clark, S. R., & Bennett, R. M. (1991). The fibromyalgia impact questionnaire: development and validation. *Journal of Rheumatology*, 18, 728-33.
- Burleson, B.R., & MacGeorge, E.L. (2002). Supportive communication. In M.L. Knapp & J.A. Daly (Eds.), *Handbook of interpersonal communication* (pp. 374-413). Thousand Oaks, CA: Sage.
- Burleson, B. R., Albrecht, T. L., & Sarason, I. G. (1994). *Communication of social support: Messages, interactions, relationships, and community*. Thousand Oaks, CA: Sage Publications.
- Buskila, D., & Cohen, H. (2007). Comorbidity of fibromyalgia and psychiatric disorders. *Current Pain and Headache Reports*, 11, 333-338.
- Butler, L. D., Koopman, C., Classen, C., & Spiegel, D. (1999). Traumatic stress, life events, and emotional support in women with metastatic breast cancer: Cancer-related traumatic stress symptoms associated with past and current stressors. *Health Psychology*, 18, 555-560.
- Cano, A., Weisberg, J. N., & Gallagher, R. M. (2000). Marital satisfaction and pain severity mediate the association between negative spouse responses to pain and depressive symptoms in a chronic pain patient sample. *Pain Medicine*, 1, 35-43.
- Caughlin, J. P., & Golish, T. D. (2002). An analysis of the association between topic avoidance and dissatisfaction: Comparing perceptual and interpersonal explanations. *Communication Monographs*, 69, 275-295.
- Cayanus, J. L., Martin, M. M., & Weber, K. D. (2004, April). *Validation of the evoking jealousy scale*. Paper presented at the Central States Communication Association Convention, Cleveland, OH.
- Centers for Disease Control and Prevention (2009). *Fibromyalgia*. Retrieved on August 5, 2011 from <<http://www.cdc.gov/arthritis/basics/fibromyalgia.htm>>
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in chronically ill. *Sociology of Health and Illness*, 5, 168-195.
- Chen, A. (2012) Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes, and fibromyalgia support groups. *Patient Education and Counseling*, 87, 250-257.

- Choy, E., Perrot, S., Leon, T., Kaplan, J., Petersel, D., Ginovker, A., & Kramer, E. (2010). A patient survey of the impact of fibromyalgia and the journey to diagnosis. *Health Services Research, 10*, 102. doi:10.1186/1472-6963-10-102
- Cline, R.J.W. (2003). Everyday interpersonal communication and health. In T.L. Thompson, A.M. Dorsey, K.I. Miller, & R. Parrot (Eds.), *Handbook of Health Communication* (pp. 285-313). Mahwah, NJ: Lawrence Erlbaum.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic medicine, 38*, 300-314.
- Cohen, S. (2004). Social relationships and health. *American psychologist, 59*, 676-684.
- Cohen, S., Janicki-Deverts, D., & Miller, G. (2007). Psychological stress and disease. *Journal of American Medical Association, 298*, 1685-1687.
- Cohen, S., Gottlieb, B.H., Underwood, L.G. (2000). Social relationships and health. In: S. Cohen, L.G Underwood, B.H Gottlieb (Eds.), *Measuring and intervening in social support*. (pp. 3-25). New York: Oxford University Press.
- Cohen, H., Neumann, L., Haiman, Y., Matar, M. A., Press, J., & Buskila, D. (2002). Prevalence of post-traumatic stress disorder in fibromyalgia patients: overlapping syndromes or post-traumatic fibromyalgia syndrome?. *Seminars in Arthritis and Rheumatism, 32*, pp. 38-50.
- Cohen, S. E., & Syme, S. (1985). *Social support and health*. San Diego, CA: Academic Press.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310-257.
- Collins, N. L., & Miller, L. C. (1994). Self-disclosure and liking: A meta-analytic review. *Psychological Bulletin, 116*, 457-475.
- Compas, B. E., Forsythe, C. J., & Wagner, B. M. (1988). Consistency and variability in causal attributions and coping with stress. *Cognitive Therapy and Research, 12*, 305-320.
- Cooper, L. (1997). Myalgic encephalomyelitis and the medical encounter. *Sociology of Health and Illness, 19*, 186-207.
- Cornman, J.C., Goldman, N., Gleib, D.A., Weinstein, M., & Chang, M.C. (2003). Social ties and perceived support two dimensions of social relationships and health among the elderly in Taiwan. *Journal of Aging and Health, 15*, 616-644.

- Coupland, N., Coupland, J., Giles, H., Hennwood, K., & Wiemann, J. (1988). Elderly self-disclosure: Interactional and intergroup issues. *Language & Communication*, 8, 109-133.
- Creswell, J.W. (2007). *Qualitative inquiry & research design: Choosing among the five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Crooks, V. A. (2007). Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach. *Social Science & Medicine*, 64, 577-588.
- Cudney, S., Butler, M., Weinert, C., & Sullivan, T. (2002) Ten rural women living with fibromyalgia tell it like it is. *Holistic Nursing Practice*, 16, 35-45
- Cunningham, M. M., & Jillings, C. (2006). Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research*, 15, 258-273.
- Cutrona, C. & Russell, D. (1990). Types of social support and specific stress: Toward a theory of optimal matching. In B.R. Sarason, I.G. Satason, & G.R. Pierce (Eds.), *Social support: An interactional view* (pp.319-366). New York: John Wiley.
- Cutrona, C. E., & Suhr, J. A. (1994). Social support communication in the context of marriage: an analysis of couples' supportive interactions. In B.R. Burleson, T.L. Albrecht, & J.G. Sarason (Eds.) *Communication of social support: Messages, interactions, relationships, and community* (pp. 113-135). Thousand Oaks, CA, Sage
- Dailey, R., & Palomares, N. (2004). Strategic topic avoidance: an investigation of topic avoidance frequency, strategies used, and relational correlates. *Communication Monographs*, 71, 471-496. doi:10.1080/0363452042000307443
- Dailey P.A., Bishop G.D., Russell I.J., & Fletcher E.M. (1990). Psychological stress and the fibrositis/fibromyalgia syndrome. *Journal of Rheumatology*, 17, 1380-1385.
- Dennis, N., Larkin, M., & Derbyshire, S. (2013). 'A giant mess'- making sense of complexity in the accounts of people with fibromyalgia. *British Journal of Health Psychology*, 18, 763-781. Doi: 10.1111/bjhp.12020.
- Derlega, V. J., Metts, S., Petronio, S., & Margulis, S. T. (1993). *Self-disclosure*. Newbury Park, CA: Sage.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, 32, 207-218.

- Dindia, K. (2000). Sex differences in self-disclosure, reciprocity of self-disclosure, and self-disclosure and liking: Three meta analyses reviewed. In S. Petronio (Ed.), *Balancing the secrets of private disclosures* (pp. 21-36). Mahwah, NJ: Lawrence Erlbaum
- Donovan-Kicken, E. & Caughlin, J. (2011). Breast cancer patients' topic avoidance and psychological distress: The mediating role of coping. *Journal of Health Psychology, 16*, 596-606.
- Dunkel-Schetter, C. (1984). Social support and cancer: Findings based on patient interviews and their implications. *Journal of Social Issues, 40*, 77-98.
- Eccleson, C., Williams, A., & Rodgers, W. (1998). Patients and professionals understandings of the causes of chronic pain: Blame, responsibility, and identity protection. *Social Science and Medicine, 45*, 699-709.
- Eckenrode, J. (1991). *The Social Context of Coping*. New York: Plenum.
- Edwards, A., Rose, L., Edwards, C., & Singer, L. (2008). An investigation of the relationships among implicit personal theories of communication, social support and loneliness. *Human Communication, 11*, 445-462.
- Epstein, S. A., Kay, G., Clauw, D., Heaton, R., Klein, D., Krupp, L., ... & Zisook, S. (1999). Psychiatric disorders in patients with fibromyalgia: a multicenter investigation. *Psychosomatics, 40*, 57-63.
- Fenlason, K. J., & Beehr, T. A. (1994). Social support and occupational stress: Effects of talking to others. *Journal of Organizational Behavior, 15*, 157-175.
- Fitzpatrick, R., Newman, S., Archer, R., & Shipley, M. (1991). Social support, disability and depression: A longitudinal study of rheumatoid arthritis. *Social Science & Medicine, 33*, 605-611.
- Fishbain, D. A., Lewis, J., Cole, B., Cutler, B., Smets, E., Rosomoff, H., & Rosomoff, R. S. (2005). Multidisciplinary Pain Facility Treatment Outcome for Pain-Associated Fatigue. *Pain Medicine, 6*, 299-304.
- Fisher, C. (2010). Coping with breast cancer across adulthood: Emotional support communication in the mother-daughter bond. *Journal of Applied Communication Research, 38*, 386-411. DOI: 10.1080/00909882.2010.513996
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.

- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, 50, 992.
- Fox, S., & Rainie, L. (2002). E-patients and the online health care revolution. *Physician executive*, 28, 14.
- Franks, H. M., Cronan, T. A., & Oliver, K. (2004). Social support in women with fibromyalgia: Is quality more important than quantity? *Journal of Community Psychology*, 32, 425-438.
- Frasure-Smith, N., Lespérance, F., Gravel, G., Masson, A., Juneau, M., Talajic, M., & Bourassa, M. G. (2000). Social support, depression, and mortality during the first year after myocardial infarction. *Circulation*, 101, 1919-1924.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Goffman, E. (1967). *Interactional ritual: Essays in face-to-face behavior*. New York: Doubleday.
- Goldsmith, D. J. (1992). Managing conflicting goals in supportive interaction: An integrative theoretical framework. *Communication Research*, 19, 264-286.
- Goldsmith, D. J. (2004). *Communicating social support*. Cambridge, England: Cambridge University Press.
- Goldsmith, D. J., Gumminger, K., & Bute, J. J. (2006). Communication about lifestyle change between cardiac patients and their partners. In R. M. Dailey, & B. A. LePoire (Eds.), *Applied interpersonal communication matters: Family, health, & community relations* (pp. 95-117). New York: Peter Lang.
- Goldsmith, D. J., Miller, L. E., & Caughlin, J. P. (2008). Openness and avoidance in couples communicating about cancer. *Communication Yearbook*, 31, 62-115.
- Goodenow, C., Reisine, S. T., & Grady, K. E. (1990). Quality of social support and associated social and psychological functioning in women with rheumatoid arthritis. *Health Psychology*, 9, 266.
- Gormsen, L., Rosenberg, R., Bach, F., & Jensen, T. (2010) Depression, anxiety, health-related quality of life and pain in patients with chronic fibromyalgia and neuropathic pain. *European Journal of Pain*, 14, 127-134.

- Greene, K., & Faulkner, S. L. (2002). Expected versus actual responses to disclosure in relationships of HIV-positive African American adolescent females. *Communication Studies*, 53, 297-317.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, 39, 133-144.
- Hale, C. J., Hannum, J. W., & Espelage, D. L. (2005). Social support and physical health: The importance of belonging. *Journal of American College Health*, 53, 276-284.
- Hallberg, L. & Carlsson, S. (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia. In-depth interviews with twenty-two female patients. *Scandinavian Journal of Caring Sciences*, 12, 95-103.
- Hallberg, L. & Carlsson, S. (2000). Coping with fibromyalgia: A qualitative study. *Scandinavian Journal of Caring Sciences*, 14, 29-36.
- Heller, K., & Swindle, R. W. (1983). Social networks, perceived social support and coping with stress. In R. D. Felner, L. A. Jason, J. Moritsugu, & S. S. Farber (Eds.), *Preventive psychology, research and practice in community intervention* (pp. 87-103). New York: Pergamon.
- Heller, T., Roccoforte, J. A., Hsieh, K., Cook, J. A., & Pickett, S. A. (1997). Benefits of support groups for families of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67, 187.
- Hellstrom, O., Bullington, J., Karlsson, G., Lindqvist, P., Mattsson, B. (1999). A phenomenological study of fibromyalgia. Patient perspectives. *Scandinavian Journal of Primary Health Care*, 17, 6-11.
- Henriksson, C. M. (1994). Living with continuous muscular pain--patient perspectives. Part I: Encounters and consequences. *Scandinavian journal of caring sciences*, 9, 67-76.
- Henriksson, C., Gundmark, I., Bengtsson, A., & Ek, A. C. (1992). Living with fibromyalgia. Consequences for everyday life. *The Clinical journal of pain*, 8, 138-144.
- Harrington, N.G. & Matthews, C.K. (1997, November). Shame-proneness among the invisibly disabled: Implications for communication with health care providers. Paper presented at the Annual Convention of Speech Communication Association, Chicago, IL.

- Horan, S. M., Martin, M. M., Smith, N., Schoo, M., Eidsness, M., & Johnson, A. (2009). Can we talk? How learning of an invisible illness impacts forecasted relational outcomes. *Communication Studies*, 60, 66-81.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241, 540-545.
- Huston, T. L., Surra, C. A., Fitzgerald, N. M., & Cate, R. M. (1981). From courtship to marriage: Mate selection as an interpersonal process. In S. W. Duck, & R. Gilmour (Eds.), *Personal relationships 2: developing personal relationships* (pp. 53–88). London: Academic Press.
- Hughes, G., Martinez, C., Myon, E., Taieb, C., & Wessley, S. (2005). The impact of a diagnosis of fibromyalgia on health care resource use by primary care patients in the UK: An observational study based on clinical practice. *Arthritis and Rheumatism*, 54, 177-183. DOI: 10.1002/art.21545
- Ingram, K. M., Betz, N. E., Mindes, E. J., Schmitt, M. M., & Smith, N. G. (2001). Unsupportive responses from others concerning a stressful life event: Development of the Unsupportive Social Interactions Inventory. *Journal of Social and Clinical Psychology*, 20, 173-207.
- Institute of Medicine Committee (US) on Advancing Pain Research, Care, and Education. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington DC: National Academies Press.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of advanced nursing*, 32, 243-248.
- Johnson, A., Wittenberg, E., Villagran, M., Mazur, M., & Villagran, P. (2003). Relational progression as a dialectic: Examining turning points in communication among friends. *Communication Monographs*, 70, 230-249.
- Juuso, P., Skar, L., Olsson, M., Soderberg, S. (2011). Living with a double burden: Meanings of pain for women with fibromyalgia. *International Journal of Qualitative Studies in Health and Well-being*, 6, 1-9.
- Kahn, R. L., Wolfe, D. M., Quinn, R. P., and Snoek, J. D. (1964). *Organizational Stress: Studies in Role Conflict and Ambiguity*. New York: Wiley
- Kaplan, B.H., Cassel, J.C. & Gore, G. (1977). Social support and health. *Medical Care*. 15, 47-58.
- Karp, D.A. (1994). Living with depression: Illness and identity turning points. *Qualitative Health Research*, 4, 6-30.

- Karp, D. & Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qualitative Health Research*, 10, 6-25.
- Keigher, S. M., & Jurkowski, E. T. (2001). Life after a national nightmare: coping with invisible illness and disability. *Health and Social Work*, 26, 211.
- Kelly, P. & Clifford, P. (1997). Coping with chronic pain: Assessing narrative approaches. *Social Work*, 42, 266-277.
- Kimberly, J. A., Serovich, J. M., & Greene, K. (1995). Disclosure of HIV-positive status: Five women's stories. *Family Relations*, 44, 316-322.
- Kool, M. & Greenen, R. (2012). Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *The Journal of Psychology*, 146, 229-241.
- Krause, M., Liang, J., & Yatomi, N., 1989. Satisfaction with social support and depressive symptoms: A panel analysis. *Psychology and Aging*, 4, 88-97.
- Kreps, G. L. (1988). Relational communication in health care. *Southern Speech Communication Journal*, 53, 344-359.
- Kroenke, C. H., Kubzansky, L. D., Schernhammer, E. S., Holmes, M. D., & Kawachi, I. (2006). Social networks, social support, and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, 24, 1105-1111.
- Kundrat, A.L. & Nussbaum, J.F. (2003). The impact of invisible illness on identity and contextual age across the life span. *Health Communication*. 15, 331-347.
- Lackner, J. B., Joseph, J. G., Ostrow, D. G., & Eshleman, S. (1993). The effects of social support on Hopkins Symptom Checklist-assessed depression and distress in a cohort of human immunodeficiency virus-positive and-negative gay men: A longitudinal study at six time points. *The Journal of Nervous and Mental Disease*, 181, 632-638.
- Lakey, B., & Drew, J. B. (1997). A social-cognitive perspective on social support. In G. R. Pierce, B. Lakey, I. G. Sarason, & B. R. Sarason (Eds.), *Sourcebook of social support and personality* (pp. 107-140). New York: Plenum Press.
- Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: a conceptual analysis. *Journal of advanced nursing*, 25, 95-100.
- Lett, H. S., Blumenthal, J. A., Babyak, M. A., Catellier, D. J., Carney, R. M., Berkman, L. F., ... & Schneiderman, N. (2007). Social support and prognosis in patients at

- increased psychosocial risk recovering from myocardial infarction. *Health Psychology*, 26, 418-427.
- Lincoln, Y & Guba, E. (1985). *Naturalistic Inquiry*. Newbery Park, Ca: Sage.
- Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, 367, 528-529.
- Lofgren, M., Ekholm, J., & Ohman, A. (2006) 'A constant struggle': Successful strategies of women in work despite fibromyalgia. *Disability and Rehabilitation*, 28, 447-455.
- Lyons, K. S., Jones, K. D., Bennett, R. M., Hiatt, S. O., & Sayer, A. G. (2013). Couple perceptions of fibromyalgia symptoms: The role of communication. *Pain*, 154, 2417-2426.
- Lyyra, T. M., & Heikkinen, R. L. (2006). Perceived social support and mortality in older people. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61, S147-S152.
- Madden, S., & Sim, J. (2006). Creating meaning in fibromyalgia syndrome. *Social science & medicine*, 63, 2962-2973.
- Matthews, C.K. (1994). To tell or not to tell: The management of privacy boundaries by the invisibly disabled. Paper presented at the annual meeting of the Western States Communication Association Conference, San Jose, CA.
- Matthews, C.K. & Harrington, N.G. (2000). Invisible disability. In D.O. Braithwaite & T.L. Thompson (Eds.) *Handbook of communication and people with disabilities: Research and Application* (pp.223-238). Mahwah, NJ: Lawrence Erlbaum Associates Inc.
- Matthias, M., Parpart, A., Nyland, K., Huffman, M., Stubbs, D., Sargent, C., & Blair, M. (2010) The patient-provider relationship in chronic pain care: Providers' perspectives. *Pain Medicine*, 11, 1688-1697. DOI: 10.1111/j.1526-4637.2010.00980.x
- Mengshoel A., & Heggen K. (2004). Recovery from fibromyalgia – previous patients' own experiences. *Disability and Rehabilitation* 26, 46–53.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey Bass.
- Merrigan, G. (2000). Negotiating personal identities among people with and without identified disabilities: The role of identity management. In D. O. Braithwaite & T.

- L. Thompson (Eds.), *Handbook of communication and people with disabilities: Research and application* (pp. 223–238). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Metts, S., & Manns, H. (1996). Coping with HIV and AIDS: The social and personal challenges. In E. B. Ray (Ed.), *Communication and disenfranchisement: Social health issues and implications* (pp. 347–364). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Miell, D. (1984). Strategies in information exchange in developing relationships: Evidence for a unique relational context. Paper presented at the Second International Conference on Personal Relationships, Madison, WI.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage
- Murray, T. L., Daniels, M. H., & Murray, C. E. (2006). Differentiation of self, perceived stress, and symptom severity among patients with fibromyalgia syndrome. *Families, Systems, & Health, 24*, 147.
- Muse, M. (1986). Stress-related, posttraumatic chronic pain syndrome: Behavioral treatment approach. *Pain, 25*, 389-394.
- Nickel, R., Egle, U. T., Eysel, P., Rompe, J. D., Zöllner, J., & Hoffmann, S. O. (2001). Health-related quality of life and somatization in patients with long-term low back pain: a prospective study with 109 patients. *Spine, 26*, 2271-2277.
- O'Brien, T. B., & DeLongis, A. (1996). The interactional context of problem-, emotion-, and relationship-focused coping: the role of the big five personality factors. *Journal of Personality, 64*, 775-813.
- O'Brien, T. B., DeLongis, A., Pomaki, G., Puterman, E., & Zwicker, A. (2009). Couples coping with stress: The role of empathic responding. *European Psychologist, 14*, 18-28.
- Ohayon, M. M. (2005). Prevalence and correlates of nonrestorative sleep complaints. *Archives of Internal Medicine, 165*, 35-41.
- Oliver, K., Cronan, T. A., Walen, H.R. & Tomita, M. (2001). Effects of social support and education on health care costs for patients with fibromyalgia. *The Journal of Rheumatology, 28*, 2711-2719.
- Östberg, V., & Lennartsson, C. (2007). Getting by with a little help: The importance of various types of social support for health problems. *Scandinavian Journal of Public Health, 35*, 197-204.

- Park, J., Lee, J., & Kim, N. (2006). "Hi! My name is Clara": The effects of self-disclosing agents on the attitude and behavior of users. Paper Presented at the annual meeting of the International Communication Association Conference, Dresden, Germany.
- Paulson, M., Danielson, E., & Söderberg, S. (2002). Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research*, 12, 238-249.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21.
- Perrot, S., Choy, E., Petersel, D., Ginovker, A., & Kramer, E. (2012). Survey of physician experiences and perceptions about the diagnosis and treatment of fibromyalgia. *BMC Health Services Research*, 12, 356. doi:10.1186/1472-6963-12-356.
- Petronio, S. (2002). *Boundaries of Privacy: Dialectics of Disclosure*. Albany, NY: SUNY Press.
- Petronio, S., & Kovach, S. (1997). Managing privacy boundaries: Health providers' perceptions of resident care in Scottish nursing homes. *Journal of Applied Communication Research*, 25, 115-131.
- Porter, L. S., Keefe, F. J., Hurwitz, H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-Oncology*, 14, 1030-1042.
- Query, J. L., & Kreps, G. L. (1996). Testing a relational model for health communication competence among caregivers for individuals with Alzheimer's disease. *Journal of Health Psychology*, 1, 335-351.
- Raheim, M. & Haland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research*, 16, 741-761.
- Rankin, S. H., & Monahan, P. (1991). Great expectations: Perceived social support in couples experiencing cardiac surgery. *Family Relations*, 40, 297-302.
- Raymond, M. & Brown, J. (2000). Experience of fibromyalgia. Qualitative study. *Canadian Family Physician*, 46, 1100-1106.
- Rodham, K., Rance, N., & Blake, D. (2010). A qualitative exploration of carers' and patients' experiences of fibromyalgia: One illness, different perspectives. *Musculoskeletal Care*, 8, 68-77. DOI: 10.1002/msc.167

- Rutledge, T., Reis, S. E., Olson, M., Owens, J., Kelsey, S. F., Pepine, C. J., ... & Matthews, K. A. (2004). Social networks are associated with lower mortality rates among women with suspected coronary disease: the National Heart, Lung, and Blood Institute-Sponsored Women's Ischemia Syndrome Evaluation study. *Psychosomatic medicine*, 66, 882-888.
- Ryan, S. (1995). Fibromyalgia: What help can nurses give? *Nursing Standard*, 9, 25-28.
- Sarason, I. G., Sarason, B. R., & Pierce, G. R. (1995). Stress and social support. In S. E. Hobfoll & M. W. de Vries (Eds.), *Extreme stress and communities: Impact and intervention* (pp. 179-197). The Netherlands: Kluwer Academic Publishers.
- Schonfeld, I. S. (2001). Stress in 1st-year women teachers: the context of social support and coping. *Genetic, Social, and General Psychology Monographs*, 127, 133-168.
- Schoofs, N., Bambini, D., Ronning, P., Bielake, E., & Woehl, J. (2004). Death of a lifestyle: The effects of social support and healthcare support on the quality of life of persons with fibromyalgia and/or chronic fatigue syndrome. *Orthopedic Nursing*, 23, 364-374.
- Segrin, C. & Tomschke, T. (2011). Social support, loneliness, recuperative processes and their direct and indirect effects of health. *Health Communication*, 26, 221-232. DOI: 10.1080/10410236.2010.546771.
- Semmer, N., Elfering, A., Jacobshagen, N., Perrot, T., Beehr, T., & Boos, N. (2008). The emotional meaning of instrumental support. *International journal of stress management*, 15, 235-251.
- Serovich, J.M. & Greene, K. (1993). Perceptions of family boundaries: The case of disclosure of HIV testing. *Family Relations*. 42, 193-197.
- Schaefer, K. M. (1995). Struggling to maintain balance: a study of women living with fibromyalgia. *Journal of advanced nursing*, 21, 95-102.
- Schaefer, K. M. (2005). The lived experience of fibromyalgia in African American women. *Holistic Nursing Practice* 19, 17-25.
- Schwarzer, R., & Leppin, A. (1991). Social support and health: A theoretical and empirical overview. *Journal of Social and Personal Relationships*, 8, 99-127.
- Seeman, T. E., & Crimmins, E. (2001). Social environment effects on health and aging. *Annals of the New York Academy of Sciences*, 954, 88-117.
- Sherbourne, C. & Stewart, A. (1991). The MOS social support survey. *Social Science and Medicine*, 32, 705-714.

- Sherman, J., Carlson, C., Cordova, M., et al. (2005). Identification of post-traumatic stress disorder in orofacial pain patients. *Journal Dental Residency*, 77, 111.
- Sherman, J. J., Turk, D. C., & Okifuji, A. (2000). Prevalence and impact of posttraumatic stress disorder-like symptoms on patients with fibromyalgia syndrome. *The Clinical Journal of Pain*, 16, 127-134.
- Siegel, K., & Schrimshaw, E. W. (2002). The perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS. *Journal for the Scientific Study of Religion*, 41, 91-102.
- Smarr, K. L., Parker, J. C., Wright, G. E., Stucky-Ropp, R. C., Buckelew, S. P., Hoffman, R. W., ... & Hewett, J. E. (1997). The importance of enhancing self-efficacy in rheumatoid arthritis. *Arthritis & Rheumatism*, 10, 18-26.
- Smyth, J. M., & Pennebaker, J. W. (2001). What are the health effects of disclosure? In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *Handbook of health psychology* (pp. 339 –348). Mahwah, NJ: Erlbaum
- Söderberg, S., & Lundman, B. (2001). Transitions experienced by women with fibromyalgia. *Health Care for Women International*, 22, 617-631.
- Söderberg, S., Lundman, B., & Norberg, A. (1999). Stuggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9, 575-587. DOI: 10.1177/104973299129122090
- Sorenson, M.R., Janusek, L., & Mathews, H.L. (2006). Perceived stress, illness uncertainty, and disease symptomatology in multiple sclerosis. *Spinal Cord Injury Nursing Journal*, 23, 1-10.
- Spiegel, D., & Kimerling, R. (2001). Group psychotherapy for women with breast cancer: Relationships among social support, emotional expression, and survival. In C.D. Ryff & B.H. Singer (Eds.), *Emotion, social relationships, and health* (pp.97-123). New York: Oxford University Press
- Stake, R. (1995). *The art of case study research*. Thousand Oaks, CA: Sage Publications.
- Stehlik, R., Arvidsson, L., & Ulfberg, J. (2009). Restless legs syndrome is common among female patients with fibromyalgia. *European neurology*, 61, 107-111.
- Stone, A. A., & Neale, J. M. (1984). New measure of daily coping: Development and preliminary results. *Journal of Personality and Social Psychology*, 46, 892-906.

- Stone, A., Shiffman, S., Schwartz, J., Broderick, J., & Hufford, M. (2003). Patient compliance with paper and electronic diaries. *Controlled Clinical Trials*, 24, 182-199.
- Sturge-Jacobs, M. (2002). The experience of living with fibromyalgia: Confronting an invisible disability. *Research and Theory for Nursing Practice*, 16, 19-31
- Surra, C. & Hughes, D. (1997). Commitment processes in accounts of the development of premarital relationships. *Journal of Marriage and the Family*, 59, 5-21.
- Terry, D. (1994). Determinants of coping: the role of stable and situational factors. *Journal of Personality and Social Psychology*, 66, 895-910.
- Thoits, P. A. (1985). Social support and psychological well-being: Theoretical possibilities. In *Social support: Theory, research and applications*, 24, 51-72.
- Thoits, P. A. (1991). On merging identity theory and stress research. *Social Psychology Quarterly*, 54, 101-112.
- Thompson, T.L., & Parrott, R. (2002). Interpersonal communication and health care. In M.L. Knapp & J.A. Daly (Eds.), *Handbook of interpersonal communication* (pp. 680-725). Thousand Oaks, CA: Sage.
- Thorne, S., McGuinness, L., Con, A., Cunningham, M., & Harris, S. (2004). Health care communication issues in fibromyalgia: An interpretive description. *Physiotherapy Canada*, 56, 31-38.
- Uchino, B. N. (2006). Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *Journal of behavioral medicine*, 29, 377-387.
- Ullrich, A., Hauer, J., & Farin, E. (2014). Communication preferences in patients with fibromyalgia syndrome: Descriptive results and patient characteristics as predictors. *Patient Preference and Adherence*, 8, 135-145.
doi: 10.2147/PPA.S53474
- Ursal, A., Lin, H., Knee, R., & Bush, A. (2012). The association between self-concealment from one's partner and relationship well-being. *Personality and Social Psychology Bulletin*, 38, 39-51.
- Ursal, A. & Lu, Q. (2011). Is self-concealment associated with acute and chronic pain? *Health Psychology*, Advance online publication.
- Van Houdenhove, B., & Luyten, P. (2006). Stress, depression and fibromyalgia. *Acta Neurologica Belgica*, 106, 149-156.

- Van Uden-Kraan, C., Drossaert, C., Taal, E., Shaw, B., Seydel, E., & van de Laar, M. (2008) Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis or fibromyalgia. *Qualitative Health Research*, 18, 405-417. Doi: 10.1177/1049732307313429
- Vangelisti, A. L. (1994). Family secrets: Forms, functions and correlates. *Journal of Social and Personal Relationships*, 11, 113-135.
- Vaux, A., Riedel, S., & Stewart, D. (1987). Modes of social support: The social support behaviors (SS-B) scale. *American Journal of Community Psychology*, 15, 209-232.
- Vincent, A., Whipple, M., Rhudy, L. (2015). Fibromyalgia flares: A qualitative analysis. *Pain Medicine*, early view. DOI:10.0000/pme.12676
- Walster, E. H., Walster, G. W., & Berscheid, E. (1978). *Equity: Theory and research*. Allyn & Bacon.
- Weber, K., Johnson, A., & Corrigan, M. (2004). Communicating emotional support and its relationship to feelings of being understood, trust, and self-disclosure. *Communication Research Reports*, 21, 316-323.
- Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors. *Social Science Medicine*, 57, 1409-1419.
- Weiner, D. K. (2007). Office management of chronic pain in the elderly. *The American Journal of Medicine*, 120, 306-315.
- Willis, T. A. (1991). Social support and interpersonal relationships. *Prosocial Behavior, Review of Personality and Social Psychology*, 12, 265-289.
- Willis T. A., & Shinar O. (2000). Measuring perceived and received social support. In S. Cohen, L. G. Underwood, B. H Gottlieb (Eds.) *Social Support Measurement and Intervention: A Guide for Health and Social Scientists*. (pp. 86-135). New York: Oxford University Press
- White, A. M., Philogene, G. S., Fine, L., & Sinha, S. (2009). Social support and self-reported health status of older adults in the United States. *American Journal of Public Health*, 99, 1872.
- Wolfe, F. (2009). Fibromyalgia wars. *Journal of Rheumatology* 36, 671-678.
- Wolf, L.D., Davis, M.C., Yeung, E.W., & Tennen, H.A. (2015). The within-day relation between lonely episodes and subsequent clinical pain in individuals with

fibromyalgia: Mediating role of pain cognitions. *Journal of Psychosomatic Research, In Press*.

Wolfe, F., Smythe, H.A., Yunus, M.B., Bennett, R.M. Bonardier, C., Goldenberg, D.L., et al. (1990). The American college of rheumatology 1990 criteria for the classification of fibromyalgia: Report of the multicenter criteria committee. *Arthritis and Rheumatism*, 33, 160-172.

Wuytack, F. & Miller, P. (2011). The lived experience of fibromyalgia in female patients, a phenomenological study. *Chiropractic and Manual Therapies*, 19, 22-30. doi:10.1186/2045-709X-19-22.

Zautra, A. J., Fasman, R., Parish, B. P., & Davis, M. C. (2007). Daily fatigue in women with osteoarthritis, rheumatoid arthritis, and fibromyalgia. *Pain*, 128, 128-135.

Ziguras, C. (2000). From patients to consumers: Is the Internet making us healthier? *Arena Magazine*, 46, 37-39.

BIOGRAPHY

Kristen Leigh Willett graduated from Salem High School in Salem, VA, in 2003. She received her Bachelor of Arts from Christopher Newport University in 2007. She received her Master of Arts in Communication from George Mason University in 2009.