

OUR STORIES ARE DIFFERENT: NARRATIVES OF FIBROMYALGIA, THE SICK ROLE,
AND LEISURE-BASED SELF-CARE

BY

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DISSERTATION

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Abstract

This study focused on the lives of people who have Fibromyalgia Syndrome (FMS), a condition resulting in chronic generalized musculoskeletal pain (Henriksson & Burckhardt, 1996). FMS is one of a number of “functional disorders,” and as a result, its legitimacy as a real disease is often called into question (Segall, 1976). The main goal of this study was to gather narratives from people with FMS in order to explore sick role theory, leisure-based self-care, constraints to daily living, and leisure-based coping for people with nonratified chronic illness. Focus groups, in-person interviews, and phone interviews were conducted with 2 men and 26 women over the course of a 3 month period. The discussion in each focus group or interview was prompted by questions from an interview guide (Patton, 1990) and was guided by grounded theory (Glaser & Strauss, 1967). The end result of my data analysis included the delineation of 6 themes as well as the creation of a set of 5 synthesis stories. The results of this study suggest that leisure-based self-care may function as an alternative to the set of steps outlined in sick role. Results also indicated that participants faced severe social, psychological, and tangible consequences of their failure to adhere to the sick role. The results were also able to add nuance and context to existing leisure research concepts, particularly leisure-based coping and leisure-based constraints.

Keywords: Fibromyalgia Syndrome, sick role theory, leisure, self-care

For my family, with love and gratitude.

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Chapter 1 - Introduction

This study focused on the daily lives of people who have Fibromyalgia Syndrome (FMS). FMS is commonly defined as chronic generalized musculoskeletal pain (Henriksson & Burckhardt, 1996; Masi & Muhammad, 1986; Russell, Vipraio, Morgan, & Bowden, 1986) and is “the second or third most common disorder presenting to rheumatologists” (Russell et al., p. 50). FMS affects approximately 2-4% of the world’s population, among them at least 6 million Americans (Barker, 2002; Henriksson & Burckhardt). The majority of those suffering from FMS are women (Barker) and no curative treatment is currently available (Henriksson & Burckhardt). FMS is categorized as one of a number of “functional disorders” such as irritable bowel syndrome, chronic fatigue syndrome and tension headache syndrome (Masi & Muhammad; Russell et al.). In general, medical researchers have suggested that these functional disorders are caused by a combination of psychological, neurological and physiological processes (Masi & Muhammad; Russell et al.). However, individual doctors and researchers put differing weight on each cause, and many believe that these illnesses are mostly psychological. As a result its legitimacy is often in question (Segall, 1976). For instance, Asbring (2001) found that some in the medical community and the public at large contest the symptoms related to FMS and, in some cases, its very existence. Due to this tenuous position in medicine and society, the lives of people with FMS are influenced not only by physical symptoms, but also by societal reactions to their illness.

Defining Health

Most recent health research, including that on Fibromyalgia, has been influenced by the World Health Organization’s definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health

Organization, 1946). This holistic definition has encouraged researchers to pursue a deeper understanding of health in terms of quality of life and also allows for explorations of healthy behaviors during illness. These broader research goals have also led to a relatively recent focus on the relationships between leisure and health (i.e. Henderson & Bialeschki, 2005; Ponde & Santana, 2000; Sallis & Linton, 2005). However, limited work has been done to examine the roles of leisure in addressing specific illnesses, and when researchers do focus on specific illnesses, they tend to focus on high-profile illnesses such as breast cancer (i.e. Parry, 2007) or Alzheimer's (i.e. Yarnal, Chick & Dattilo, 2006). While this work is certainly valuable, it excludes people with so-called "non-ratified" illnesses, such as those who suffer from Fibromyalgia and other functional disorders. Unlike the widespread support and understanding afforded to women with breast cancer or seniors with Alzheimer's, people with chronic pain and fatigue disorders tend to be misunderstood by friends and family and dismissed by the medical establishment (Henriksson & Burckhardt, 1996). As a result, understanding the leisure experiences of people with Fibromyalgia may help to shed light on the confluences of health, sociology, and leisure in new and socially relevant ways.

Sick Role Theory

In addition to understanding how people react to illness on a psychological level (i.e. coping or self-care), it is also important to understand how illness works on a societal level. As a result, sick role theory, developed by Talcott Parsons in the 1950's, provided both a theoretical framework as well as a sociological lens for this study. Parsons' (1951) sick role, functioning within a structural-functionalist framework, was designed to "explain how social structures deal with the consequences of sickness and illness" (Miczo, 2004, p. 348). At the heart of Parsons' theory is the suggestion that society has four main rules for the behavior of ill individuals: first,

a sick person is relieved of some social duties and responsibilities; second, while society does not consider a sick person at fault for being sick, they must nonetheless make an effort to get better; third, the sick person is required to seek medical guidance for recovery and comply with doctor's orders; and fourth, a sick person must recognize that being sick is undesirable and therefore must want to get better so that they can resume their duties and responsibilities in life (Arluke, Kennedy, & Kessler, 1979; Crossley, 1998; Parsons, 1951; Shilling, 2002).

In addition to shaping many of the ways that sociologists interpret the illness experience, sick role theory also provides an interesting window into the cultural values that guide society's interpretation of illness behavior. For instance, some scholars have drawn parallels between sick role theory and Western Protestant-inspired views of work and illness wherein work is highly regarded and sickness is considered socially dysfunctional (Crossley, 1998). This cultural context is evident in that the final responsibility of a patient, according to sick role theory, is to recognize that being sick is *undesirable* and work towards returning to normal life with all its duties and responsibilities (Arluke et al., 1979; Crossley; Parsons, 1951; Shilling). As Shilling (2002) explained, although a validated sickness may allow for a break from normal everyday activities, it does create other new responsibilities for the patient. For instance, a patient who does not make visible efforts towards recovery may be perceived as lazy or taking advantage of the system, a perception that will result in social ramifications. These ramifications may be particularly relevant to patients who cannot fully achieve the sick role, such as those with FMS who will not recover, often do not receive a firm and quick diagnosis, and have trouble interacting with the medical professionals who serve as the gatekeepers of the sick role.

Therefore, applying sick role theory to the experiences of people with FMS allows for a deeper understanding of the social, psychological and emotional tolls of their illness. As Glenton

(2003) explained, chronic conditions like FMS are sicknesses you “have to fight to get,” and as a result achieving the sick role is like achieving societal validation of one’s symptoms (p. 2249). Furthermore, Stewart and Sullivan even suggested that examining chronic illnesses like FMS through the lens of the sick role will result in more vigorous sociological theories about sickness and health. In doing so they pointed out that traditional sick role research based on acute illness experiences often focuses on the stages of the illness process at which “social consensus and definitional clarity” are likely to exist and that this focus has inhibited our ability to understand “the process by which normative consensus [about an individual’s health or illness] is achieved, the role of both physicians and patients in that process, and the consequences of the failure to achieve consensus” (Stewart & Sullivan, p. 1398). As a result, exploring the sick role as it relates to FMS may not only shed light on the frustrations of those with chronic nonratified illnesses, but may also result in a more robust and comprehensive understanding of the impacts of the sick role.

Leisure-Based Self-Care

In addition to its grounding in the sociology of health, this study was also situated in the leisure sciences because of its focus on the activities that people choose to do, cannot do or want to do during their free time. This approach is particularly applicable to the current study because of its inherent grounding in the study of choice, ability and power; all of these issues are relevant to people with non-ratified illness like Fibromyalgia.

In particular, the current study will focus on leisure-based self-care in the everyday lives of people with Fibromyalgia Syndrome. This concept was first suggested by Son and Hutchinson (2009), and it combines self-care literature with leisure literature. Briefly defined, self-care (as conceptualized outside of a leisure context) encompasses the broad scope of

measures that a person takes to relieve or treat an illness or condition outside of a medical setting (Andersson, Ejlertsson, Leden & Schersten, 1999). It is the most frequently reported behavioral response to headaches, body aches, fatigue, and colds, and many people solely use self-care measures to treat a variety of symptoms (Stoller, Forster & Portugal, 1993). As a result, self-care is distinct from alternative care in that alternative care (i.e. acupuncture or homeopathy) involves a professional or outside practitioner whereas self-care is self-administered (Andersson et al., 1999).

Previous research (i.e. Andersson et al.; Jordan et al., 2002; Stoller et al., 1993) has indicated that self-care is an especially common complement to traditional medical treatments among patients with chronic pain conditions. The most commonly used self-care measures most studies included the application of heat or an increase in rest. Secondary measures included physical activities such as walking, jogging and swimming as well as modifications to working conditions or schedules. As these examples suggest, leisure and self-care often intersect in that leisure time provides a forum for many self-care activities. Son and Hutchinson (2009) suggested that leisure may be one of the few arenas of daily life wherein people are able to “experience *success* in their efforts to take better care of themselves” (p. 27, emphasis original).

However, despite a strong body of evidence indicating that leisure activities are integral and important parts of many patients’ self-care practices, the self-care literature is largely void of the specific mention of leisure as a component of self-care (Kleiber et al., 2008; Son & Hutchinson, 2009). Therefore, contributions to Son and Hutchinson’s initial conceptualization of leisure-based self-care may prove particularly useful in understanding the complex relationships among leisure, health and well-being. The current study was able to address some of these complex relationships by incorporating leisure-based self-care.

Constraints to Leisure

Constraints to leisure and daily life often play a large role in the lives of people with FMS and other chronic pain conditions. Although fatigue and weakness are the most commonly reported constraints among this group (Richardson & Ream, 2007), most patients report a wide range of interruptions to their daily lives and leisure routines (Jordan et al., 2000). As a result, chronic pain may not only inhibit leisure but may also mean that some forms of leisure are no longer leisure because they do not produce the sort of positive outcomes that we expect from our free time activities.

Leisure and health research has suggested more complex views of constraints and constraints negotiation which were particularly applicable to the current study. For instance, Loucks-Atkinson and Mannell's (2007) study of people with FMS found that even the participants who made a lot of effort to negotiate their leisure constraints were nevertheless limited by the powerful nature of the pain, discomfort and fatigue they experienced. As a result, the authors suggested that while motivation and desire to negotiate constraints were important aspects of constraints experiences, they could not always be counted on ensure that participants were able to overcome barriers to leisure participation. Moreover, Kleiber, Hutchinson and Williams (2002) found that people's roles, relationships, attitudes towards the future and preferred activities are likely to be disrupted at the onset of chronic illness or other negative life events. As a result, after the initial onset of a negative life event, people are likely to stop or drastically alter their leisure lives in reaction to the event. However, once time has passed people may begin to resume aspects of their leisure lives or seek out leisure-based outlets for coping or self-care. Therefore, Kleiber et al. (1995, 2002) suggested that the initial (and at times continued) loss of leisure activities and social relationships may be one of the most definitive definitions of

the illness experience. Indeed, participants in the current study frequently struggled with FMS-related constraints to their leisure, and as a result, constraints literature was particularly relevant to interpreting the results of this study.

Leisure-Based Coping

In addition to recognizing the FMS-related limitations placed on participants' leisure, it was also important to address the potential for leisure to provide a space for participants to cope with the symptoms and implications of their illnesses. In addition, leisure activities also provide people with a source of power and control over their own lives, and as a result, leisure activities that are undertaken specifically to cope with stress may be particularly powerful tools for marginalized groups such as people with chronic nonratified illnesses (Iwasaki, 2006).

Kleiber et al. (2002) defined coping as “the attempt to lessen physical and/or psychological stress or negative feelings associated with problematic experiences” (p. 223). This process is often linked to leisure as Hutchinson, Loy, Kleiber and Dattilo (2003) explained, “Leisure has been hypothesized to serve as a coping resource by buffering the impact of negative life events through distraction, generating optimism, and enabling individuals to preserve a sense of self” (p. 144). In this way coping is distinct from adjustment in that adjustment is a longer-term process that includes adaptation and acceptance whereas coping refers to ongoing actions that help even well-adjusted people deal with the daily effects of a disease or negative life event (Hutchinson et al.).

Leisure time in particular may provide an appropriate venue for the sorts of mechanisms that help with these daily struggles. As Kleiber et al. (2002) noted, while the free time activities of people with chronic illness or significant negative life events “may not be experienced as ‘pure’ leisure (i.e. as self-determined, intrinsically motivated) there is relative freedom in the

ability to experience some choice and control, if only to create a temporary separation from the stressors associated with the negative life event” (p. 226). As a result, coping may be an important and yet variable part of the lives of people with chronic illness. In particular, coping may help people “escape the restrictions of their [ill] bodies” and provide “social situations where evidence of their disabilities [is] limited” (p. 226). The current study explored leisure-based coping within the narratives of people with Fibromyalgia Syndrome in order to provide additional insight into the roles of leisure-based coping in the daily lives of people with chronic illness.

Purpose of the Study

The main goal of this study was to gather narratives from people with Fibromyalgia Syndrome (FMS) in order to shed light on the sick role within the context of Fibromyalgia Syndrome. Secondary goals included understanding the relationships among leisure, self-care, constraints and coping for people with nonratified chronic illness. To explore these questions I conducted focus groups, in-person interviews and phone interviews with a total of 28 people who had been diagnosed with Fibromyalgia Syndrome. I wanted to understand participants’ negotiations of the sick role because much of the literature suggests that these negotiations are problematic processes for people with chronic illnesses. Additionally, I wanted to explore whether leisure activities played a role, positively or negatively, in Fibromyalgia patients’ negotiation of the sick role. Secondly, I wanted to understand the potential roles of leisure generally in the overall illness experiences of people with Fibromyalgia.

As a result, the set of research questions that guided this study were:

1. Do the narratives of patients with FMS reflect the influence of the sick role? If so, how?

- a. If so, do their narratives indicate that they are able to fulfill their obligations under the sick role?
 - b. How does their successful or unsuccessful negotiation of the sick role influence their daily lives?
2. Are leisure-based self-care practices utilized by participants in this study?
 - a. If so, what types of leisure-based self-care practices, including coping, are used?
 - b. If so, what are the effects of these practices on the daily lives of participants?
 3. Do participants in this study experience constraints, particularly leisure-based constraints, as a result of Fibromyalgia Syndrome? If so, how are these constraints negotiated, if at all?

Study's Contributions

This study was able to address several gaps in the literature as well as provide an understanding of the ways that leisure-based self-care may function as an alternative to the set of steps outlined in sick role. In particular, the experiences of participants in this study indicated that they had a strong desire to follow the sick role script despite the low likelihood of being able to do so successfully. Moreover, participants' narratives illustrated their aspiration to receive the benefits of the sick role, namely societal acceptance of their illness, a meaningful diagnosis, effective treatment, and an eventual recovery/return to normalcy. Participants did differ, however, in their beliefs about the permanence of their condition as some felt that they could eventually recover using leisure-based self-care whereas others felt that they could simply manage their symptoms until medical science discovers a cure.

As a result, many participants in this study displayed a certain amount of agency in their use of leisure-based self-care as an alternative framework for accessing the benefits of the sick

role. Previous research has not linked these two concepts, however an examination of the literature combined with the experiences of participants in this study indicates that empowerment in an illness context is something of a double-edged sword. This discussion is new to the literature, and helps to fill the gaps in our understanding of agency, the sick role, and illness.

This study was also able to shed light on the social, psychological, and tangible ramifications of participants' failures to adhere to the sick role. Few, if any, studies of the sick role have described these consequences from a patient's perspective. Moreover, the narratives presented here were also able to add nuance and context to existing leisure research concepts, particularly leisure-based coping and leisure-based constraints. Specifically, participants' experiences indicated that coping is a vital part of living with a chronic illness like Fibromyalgia, and that the ability of leisure to provide spaces for joy and happiness are paramount. On the other hand, the experiences of participants in this study also indicated that people with chronic nonratified illnesses such as Fibromyalgia are likely to be severely constrained in their ability to participate in the activities of daily life. While participants were able to negotiate some of these constraints through measures such as making choices or modifying activities or equipment, most if not all still experienced a severe limiting of their leisure repertoires.

Finally, it is important to note that the significance of this project lies not only in making a contribution to the larger body of leisure and health research, but also in creating a space for the voices of a medically marginalized group whose experiences have been understudied in leisure research contexts. It is my hope that including the voices of people with Fibromyalgia will humanize their experiences and bring attention to their medical and leisure needs. Indeed, when I asked study participants themselves what hopes they had for this project, many of them indicated that increasing understanding about and acceptance of FMS was vital. They also

mentioned more pragmatic goals such as providing exercise classes just for people with Fibromyalgia or even creating a telephone support group for people who wanted to talk about their experiences with others but who perhaps did not have the time or mobility to visit an in-person support group. As a result the goal of this study was to provide both theoretical as well as practical contributions.

Chapter 2 – Literature Review

The study of chronic illness, and in particular Fibromyalgia Syndrome, is complex and multidimensional. As a result, I conducted a focused literature review centered on the concepts directly linking Fibromyalgia, sick role theory, and leisure. The following chapter will begin with a discussion of Fibromyalgia, in particular its symptoms, impacts and proposed treatments. Next I will examine chronic illness as a whole, specifically health disparities linked to chronic illness. Doing so will illustrate the differences between FMS and other chronic ailments. Following that section I will conduct a brief overview of leisure and health research, especially research involving FMS. The next section will focus on self-care, and explicitly the types of illnesses that loan themselves to self-care as well as the role of leisure in self-care. Next I will examine coping framed within the chronic illness experience as well as the roles of leisure in coping with illness. Finally I will explore sick role theory including its impacts, relationship to chronic illness, and applicability to FMS in particular. Other concepts such as constraints, empowerment and agency will also be addressed; however, these ancillary concepts will not constitute the main focus of this study.

Fibromyalgia

Fibromyalgia Syndrome (FMS) is commonly defined as chronic and generalized musculoskeletal pain, fatigue and weakness (American College of Rheumatology, 2007; Henriksson & Burckhardt, 1996; Masi & Muhammad, 1986; & Russell et al., 1986). FMS is “the second or third most common disorder presenting to rheumatologists” (Russell et al., p. 50) and affects approximately 6 million Americans, most of them women (American College of Rheumatology; Barker, 2002; Henriksson & Burckhardt). Although it is estimated that Fibromyalgia affects on average 3.4% of American women and 0.5% of American men,

diagnoses increase in prevalence with increased age so that an estimated 7% of American women over the age of 60 have FMS (Goldenberg, 1999).

Beyond these statistics, there is very little information available about people who are diagnosed with FMS (i.e. race, class or ethnicity). Moreover, the diagnosis of Fibromyalgia itself is difficult and in many ways controversial because there are no objective biological markers (i.e. findings that would show up on X-rays or in blood tests) indicating its existence. As a result, even though FMS was officially recognized in the 1990's by the American Medical Association, the World Health Organization, and other medical groups, many individual practitioners still doubt whether or not it is a "real" illness (Wallace & Wallace, 2002, p. ix). For example Ann, a participant in this study who was eventually diagnosed with FMS, was told by one doctor that she had "Internet disease," in other words, she was not really ill, she had just read about Fibromyalgia on the Internet and subsequently convinced herself that she had FMS. As a result of the prevalence of this kind of attitude towards FMS, patients in Glenton's (2003) study of chronic pain explained that having a chronic pain condition is "a lot about being believed" (p. 2244). Similarly Werner, Isaksen and Malterud (2004) suggested that Fibromyalgia patients "repeatedly find themselves being questioned and judged either to be not ill, suffering from an imaginary illness, or [they are simply] given a psychiatric label" (p. 1036). As a result, FMS largely remains a diagnosis of omission called upon only when all other causes have been ruled out (American College of Rheumatology); and this status has led many researchers (i.e. Lonardi, 2007; Werner et al., 2004) to call it an "invisible" illness. As a result of this tenuous status, FMS treatment is rarely well coordinated and patients are often given conflicting advice by multiple health professionals (Glenton, 2003; Lonardi, 2007). As Glenton (2003) paraphrased, chronic pain conditions like FMS are sickness you "have to fight to get" (p. 2249).

Despite difficulties garnering recognition for FMS among many in the medical population, rheumatologists regularly treat FMS patients and in doing so they distinguish FMS from rheumatoid arthritis or osteoarthritis due to its unique presentation of widespread pain, significant fatigue, and related headaches or sleep disturbances (Goldenburg, 1999). Nevertheless although it is distinct from arthritis and other systemic disorders, FMS is complex in that it often co-exists with other conditions. For instance, Goldenburg found that 10-40% of patients with lupus and 10-30% of patients with rheumatoid arthritis also suffer from FMS. Moreover, FMS is also commonly associated with other systemic disorders such as Chronic Fatigue Syndrome and depression. As a result of its hazy presentation and lack of objective markers, FMS has been called a functional, as opposed to an organic, disorder which implies that the root cause of FMS symptoms are emotional or psychological and not physiological (Goldenburg, 1999). This vague category of illnesses also includes Irritable Bowel Syndrome (IBS), Chronic Fatigue Syndrome (CFS), Tension Headache Syndrome (THS), and others, all of which overwhelmingly affect women (Masi & Muhammad, 1986; Russell et al., 1986) and many of which co-occur in patients diagnosed with FMS (Goldenburg). In fact, Goldenburg suggested that FMS, CFS and IBS are so similar and “overlap so extensively that it may be concluded that each represents different presentations of the same general condition” and “therefore, little value exists in worrying whether a patient has FMS, CFS, or IBS—or all 3 disorders” (p. 778). This lack of distinction adds even further complication to a Fibromyalgia diagnosis. As a result, the 6 million Americans eventually diagnosed with FMS each year had to visit an average of 4 doctors before receiving their diagnosis (Wallace & Wallace, 2002).

Treating FMS. Unfortunately, there is no cure for FMS although full recoveries have been reported (Henriksson & Burckhardt, 1996). The American College of Rheumatology

(ACR) suggests that physicians treat FMS as a chronic illness and manage it with a combination of drugs as well as non-medical treatments such as relaxation, exercise and social support. The exact formula for treatment varies, however, because the level of complication accompanying FMS varies. For instance some patients are able to continue full or part-time work while others must withdraw from work and collect unemployment or disability payments (Asbring, 2001). However, despite these variations in the level of functioning, studies of FMS patients seem to report the same main consequences of FMS: physical disability, limited social lives, and the psychological burden of living a life in almost constant pain (Hensing, Sverker, and Leijon, 2007). As a result, FMS is much like other chronic pain disorders in that it results in “profound effects on patients’ sense of self” (Kleiber, Reel & Hutchinson 2008, p. 321).

Receiving help for FMS symptoms is easier for some patients than others (Henriksson & Burckhardt, 1996). For example, Henriksson and Burckhardt’s study of Swedish and American women with FMS found that US government policies and attitudes meant that the majority of American women with FMS still work full-time whereas only half of Swedish women do because they are more readily able to collect disability pay. This discrepancy may be related to the Swedish approach to healthcare (i.e. that it is universal and widely available) but may also indicate that the Swedish medical establishment is more accepting of FMS. Whatever the cause, this disparity not only illuminates the pervasiveness of doubt about the condition in the United States, but also illustrates the ways in which this doubt is translated into policies which impact people’s everyday lives. These policy impacts are important primarily because of the links between unemployment, health status and low socioeconomic status (Finlayson et al., 1998). Moreover, research also indicates that FMS patients who are able to claim disability have more time for personal care activities such as pain management or taking extra time to perform daily

tasks (Henriksson & Burckhardt). As a result, people's everyday experiences with FMS are inextricably linked to their degree of symptoms, level of structural support, and ability to take the time to properly manage those symptoms.

Chronic Illness

This study utilizes the World Health Organization (WHO) definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1946, p. 2). I have also taken into account Kleinman, Eisenberg and Goods' (1978) differentiation between illness (a personal experience), sickness (a socially ratified experience) and disease (a biomedical event confirmed by medical professionals). This paradigm suggests that illnesses are the least socially acceptable form of ill health as they create no visible markers (i.e. coughing, pale skin or broken bones) and they are not sanctioned by a doctor. As a result, recognition of the differentiation among these three categories along with the WHO holistic definition of health provides a useful framework for examining Fibromyalgia as a socially stigmatized chronic illness.

Normative definitions of sickness are often based on what are called acute or temporary diseases. These diseases, such as influenza or even heart attack, often present a relatively clear set of symptoms which result in a relatively clear treatment process (Stewart & Sullivan, 1982). In contrast, chronic conditions such as diabetes, arthritis or FMS are permanent and continuing in nature (Stewart & Sullivan). Moreover in many instances, particularly in the case of functional disorders, the initial symptoms of chronic conditions are “mild, nondisabling and vague” (p. 1397). Patients with these illnesses usually begin their diagnosis processes with similar expectations and goals as those with acute conditions; however, unlike patients with acute diseases, patients with chronic conditions often present with symptoms that are not clearly

defined. As a result, the time between their initial doctor visits and their eventual diagnosis may be quite prolonged. This difference alone may cause significant psychological hardship for patients with chronic conditions. Add to that the fact that, even in the case of a concrete diagnosis, effective treatments for most chronic conditions remain elusive and it becomes clear that the chronic illness experience is quite distinct from an acute one.

As a result of this difficult process, Werner et al. (2004) suggested that chronic conditions result in “biographical or continual disruption[s] of a person’s ongoing life, touching the individual’s sense of self or even causing a loss of self” (p. 1036). Moreover, Butler (1970) and Miczo (2004) suggested that chronic illness in particular may be conceptualized as forms of social deviance in that patients are unable to perform their socially defined roles and instead exist in a sort of liminal state within society. As Butler explained, “the incapacity which illness induces [in people] at the biological level is expressed behaviorally as a disruption of normal role relationships” (p. 245). Similarly Lonardi (2007) found that chronic illnesses “introduce sharp discontinuity” into people’s lives that affects their daily routines, personal identities, and independence,” (p. 1621) and furthermore the effects of long-term illness often “go far beyond the individual patient and [have] disrupting effects on the family and the community” (p. 1619). As a result, the recognition of the sociological impacts of illness alongside utilization of the WHO definition of health provides a rich context for interpreting the narratives of FMS patients who, in all likelihood, experience negative psychological and social impacts of their illnesses in addition to physical discomfort.

Illness Prestige. In addition to the heightened social impacts of chronic illnesses, disparities in treatment are also common and may result in measurable negative effects on patients’ lives. For instance Album and Westin (2008) found that doctors conceptualize specific

illnesses in terms of where they fall along a hierarchy of prestige. The level of prestige accorded to each illness seemed to be related to the typical course of the disease (i.e. Is it life threatening?), the treatment required for the disease (i.e. How much will technology help? How effective is medical intervention?) as well as by the typical patient affected (age, gender, disfigurement, helplessness). Along this spectrum the authors noted that myocardial infarction (heart attack), brain tumors and leukemia were ranked the highest in prestige while anxiety disorders, eating disorders and other illnesses with strong psychological components were ranked much lower. FMS specifically was ranked the lowest of all 38 conditions listed, and the authors suggested that this ranking was due to multiple violations of prestige including the presence of a psychological component and the fact that FMS primarily affects women.

In addition to suggesting that the low prestige of FMS may result in societal stigma, Album and Westin (2008) also pointed out that specific disease categories are used for administrative and even economic purposes. These additional uses may significantly impact patients' lives as they affect the validity of insurance and disability claims. These real world ramifications of medical hegemony are all the more salient in the lives of people with FMS. As the Album and Westin stated, "If diseases are proven to be prestige ranked, [then] it is likely that considerations other than strictly medical ones tacitly influence medical decisions" (p. 183). The impacts of these tacit decisions are likely to impact the experiences and narratives of people with FMS.

Leisure's Study of Health

As a result of the complex sociological influences on health, a wide variety of social science-based approaches to health research exist. Most recent among these is the work of leisure researchers. Currently most leisure and health researchers follow either an active living

model focused on active lifestyles as prevention for disease, or a social ecology model linking physical and social environments to health outcomes by examining the aspects of people's environments that promote or constrain healthy behaviors (Henderson & Bialeschki, 2005). However, it has been argued that these two approaches focus too heavily on health as the absence of disease and look too narrowly at physical activity as the key leisure behavior responsible for promoting and maintaining health. As an alternative, Shaw (2000) suggested that leisure and health research is strongest when it is both interdisciplinary and socially relevant. She asserted that because "leisure is neither the sole cause nor the sole solution to any one problem," leisure and health research must, by definition, be collaborative (p. 149).

As a result, work in health and leisure has taken up the call for a more holistic approach. For example, Yarnal, Hutchinson and Chow (2006) used the case of Alzheimer's to argue for the importance of research relationships between the leisure and health fields. To do so, they illustrated the ways in which people studying enriching environments for Alzheimer's patients must understand leisure research just as leisure researchers studying play must understand biomedical research and genetic and biological determinants of behavior. Similarly, Parry and Shaw's (1999) examination of menopause as well as Parry's (2007) exploration of breast cancer survivorship noted that previous leisure and research has largely followed a narrow medical model which did not contextualize women's lives or seek to understand the links between mind and body. As a result, both studies highlighted the efforts of women who pursued alternative, often active or leisure-based, methods of seeking mental, physical, emotional and spiritual health. In the case of cancer survivors, this outlet was dragon boat racing whereas in the context of menopause the outlets encompassed a wide spectrum of leisure activities.

Glover and Parry (2009) not only took a holistic approach to health but also combined the study of health with the study of place meaning. Specifically they wrote about the physical, social and emotional benefits of social clubs held in distinct locations, or “third places,” and designed specifically for cancer patients. The authors found therapeutic outcomes of these clubs related to escape from stressors, camaraderie with fellow cancer patients, and the development of an environment suited to either confronting or distancing from cancer-related problems. Additionally they were able to suggest that leisure and health literature needs to more specifically address place meanings, where applicable, in the study of health.

Finally Son, Yarnal and Kerstetter (2010) made interesting and relevant links among social capital, volunteerism, and both individual and communal health. To do so the authors explored the role of a women’s leisure club, the Red Hat Society®, as an outlet for creating social support, civic engagement and the idea of sisterhood among middle aged and older women. In doing so they suggested that the sense of community, commonality and volunteerism fostered by the club translated not only into social capital but also into an overall sense of individual and communal health. This approach to health was interesting in that it considered both individual and communal health and focused specifically on the role of social support and civic engagement in creating well-being.

The above examples illustrate the strengths of conducting leisure research without defining health too narrowly; moreover, these studies suggest that there are ways to be healthy even when you are ill, and that leisure is one component of doing so. However, these sorts of studies are still relatively underrepresented in leisure research as many studies continue to focus on the health benefits of physical exercise, park space or organized fitness opportunities.

Leisure and FMS. As a result, studies examining holistic aspects of health, especially as they exist within a specific illness setting, remain rare. Moreover, the studies that do exist tend to focus on high-profile illnesses such as breast cancer (i.e. Parry, 2007) or Alzheimers (i.e. Yarnal et al., 2006) and avoid illnesses like FMS. While this work is certainly valuable, it neglects a large group of people who suffer from non-ratified chronic illnesses. In fact, only one FMS study has been conducted within the leisure field (Loucks-Atkinson and Mannell, 2007), but this study did not include a holistic approach to health. Instead the authors mailed surveys to over 200 FMS patients in Canada and used the resulting data set to seek support or lack of support for a variety of constraints negotiation concepts, namely Hubbard and Mannell's (2001) constraints-effects mitigation model. As a result of their work the authors were able to find support for Hubbard and Mannell's model and even suggest that it be extended to include negotiation-efficacy. However, their study was not designed to explore the everyday experiences of people with Fibromyalgia Syndrome nor was their intent to explore the various health- or leisure-related aspects of the illness. As a result, their work was not able to inform the sociological aspects of the current study.

Instead many of the studies of leisure in the lives of people with FMS or other functional disorders occur outside the leisure field, and yet these studies are beginning to reveal a very complicated picture of the leisure experiences of people with FMS (i.e. Crooks, 2007). For instance Crooks (2007) used an SIP test (Sickness Impact Profile) to examine what she called the "daily geographies and life worlds" of women with FMS. In doing so she found that out of a wide variety of categories (i.e. work, sleep/rest, mobility, social interaction, recreation/pastimes, alertness behavior) "recreation and pastimes" was second only to "alertness behavior" as an area of life that her study participants felt had changed most since their Fibromyalgia diagnosis. In

particular, many of the women in Crooks' study indicated that they had given up or drastically reduced their participation in physical activity, hobbies, and recreational activities. At the same time, 89% of Crooks' sample reported an increase in participation in passive leisure time activities such as television watching. This loss in leisure repertoire subsequently resulted in reductions in the amount of geographical space that women inhabited and frequented. For example Avril, one of Crooks' (2007) participants had,

Started to participate in pool therapy and when that became too strenuous she took mile long walks in her neighborhood until those also became too taxing. Her transition to becoming a less active woman was one that happened over both time and space. Tennis took her out of the neighborhood, swimming was done close to home, and walks were done around the block, until finally most of her physical recreation came from the everyday activities she engaged in within the home (p. 584).

Avril's narrative illustrates the ways that increasingly limited leisure choice can also result in increasingly limited mobility and a reduction in experiences and interactions.

Constraints to Leisure and Daily Living

As the previous sections suggest, constraints to leisure and daily life often play a large role in the lives of people with FMS and other chronic pain conditions. Although fatigue and weakness are the most commonly reported constraints among this group (Richardson & Ream, 2007), most patients report a wide range of interruptions to their daily lives and leisure routines (Jordan et al., 2000). For instance a substantial percentage (45.5%) of participants in Jordan et al.'s study indicated that their arthritis pain limited their movement, 43.1% said that it caused them to cut down on errands and daily activities, 33.4% said that it kept them from enjoying leisure and hobbies, and 32.8% said that it kept them from sleeping normally (p. 145). Similarly the most

commonly reported constraints among MS patients in Finlayson et al.'s (1998) study included difficulty using the stairs, doing yard and housework, and maintaining a reliable work schedule. Likewise Hensing et al.'s (2007) study of chronic pain found that the majority of participants experienced difficulties performing daily activities, remaining physically mobile, and keeping up with their social lives. Crooks (2007) also suggested a relationship between FMS and social isolation, in particular participation in social activities. She pointed out that not only did women with FMS cut down on the amount and types of leisure pursuits that they engaged in, but they also felt less able to make plans with friends and family because they did not know how they would feel in a day, a week or a month. As a result, many women Crooks spoke with had either completely ceased social activities or had modified or reduced those activities so as to make them manageable. These changes to their leisure lives resulted in more widespread impacts related to physical health, mental health and emotional and social wellbeing.

Similarly, Johansson, Hamburg, Westman and Lindgren's (1999) study of the meanings of women's pain found that the pain of FMS effectively ruined the pleasurable outcomes of some participants' favorite leisure activities. More specifically Jordan et al. (2000) found that chronic arthritis pain completely prevented one-third of their study participants from engaging in activities for pleasure or recreation. As a result, chronic pain may not only inhibit leisure but may also mean that some forms of leisure are no longer leisure because they do not produce the sort of positive outcomes that we expect from our free time activities.

Understanding constraints. Although alternative models have been suggested (i.e. Henderson & Bialeschki, 1993), leisure research has traditionally categorized constraints into three main categories: structural, interpersonal and intrapersonal (Crawford & Godbey, 1987). Structural constraints, such as finances, work schedule, and family life-cycle intervene between

leisure preference and actual leisure participation. These constraints are often thought of as the easiest to overcome. Interpersonal constraints such as discrimination or lack of leisure partners are the result of relationships with others and may also affect leisure participation. Finally intrapersonal constraints, such as stress, depression, and anxiety involve psychological states and attributes which interact with leisure preferences. These constraints may be the hardest to overcome because they come from within and directly affect a person's ability to act (Crawford & Godbey).

Nevertheless, constraints in all three of these categories may be negotiated or overcome. For instance Jackson and Rucks (1995) suggested that behavioral negotiation strategies such as changes to leisure activity selections (i.e. staying home to watch TV instead of spending money to go to a movie) or changes to non-leisure aspects of life (i.e. shifting one's work schedule) may help most people overcome constraints to their leisure. If these strategies do not work, they suggested that cognitive changes (i.e. devaluing the leisure activity itself) could be used to postpone leisure until a better life stage. Constraints negotiation has also been linked to motivation. For instance Hubbard and Mannell's (2001) constraints-effect-mitigation model suggests that the more motivated a person, the more likely they are to overcome constraints and the more motivated a person, the stronger their negotiation efforts.

However, leisure and health research has also suggested more complicated views of constraints and constraints negotiation, and these views are particularly applicable to the current study. For instance Loucks-Atkinson and Mannell's (2007) study of people with FMS found that even the participants who made a lot of effort to negotiate their leisure constraints were nevertheless limited by the powerful nature of the pain, discomfort and fatigue they experienced. As a result, while motivation and desire to negotiate were important, these methods could not

always be counted on to ensure that participants overcome barriers to leisure participation. Similarly participants in Hensing et al.'s (2007) study of chronic pain frequently reported that despite their use of constraints negotiations, they often needed to significantly shorten the amount of time they participated in activities or even give up those activities altogether in order to compensate for their pain and fatigue.

In another particularly relevant example, Kleiber, Brock, Lee, Caldwell, and Datillo (1995) found that people who have suffered a severe and chronic injury often also experience severe consequences in their leisure lives. Specifically the participants in Kleiber et al.'s study spoke about lost abilities, disrupted relationships, and shrinking social worlds. Not only did these experiences alter their leisure lives but so did the physical limitations of their new injury. As Kleiber, Hutchinson and Williams (2002) noted that roles, relationships, attitudes towards the future and preferred activities are likely to be disrupted at the onset of chronic illness or other negative life events. As a result, at least initially, "leisure is more likely to be a casualty of negative life events than a solution for coping with them." In other words, after the initial onset of a negative life event people are likely to stop or drastically alter their leisure lives in reaction to the event. However, once time has passed people may begin to resume aspects of their leisure lives or seek out leisure-based outlets for coping or self-care. Therefore, Kleiber et al. (1995 & 2002) suggested that the initial (and at times continued) loss of leisure activities and social relationships may be one of the most definitive definitions of the illness experience, especially in the case of chronic illness.

These suggestions have some interdisciplinary support. Although researchers outside the leisure field do not always use the same terminology to describe constraints and constraint negotiation as researchers within the field, many studies of illness experiences nevertheless

address similar issues. For instance Hensing et al. (2007) noted that patients with chronic neuropathic pain face what the authors called “dilemmas” caused by the pain and fatigue of their illness (p. 150). Commonly mentioned dilemmas included difficulties with: the performance of household chores, participation in physical activity, endurance over the course of the day, and the ability to maintain social networks. Although some participants in Hensing et al.’s study chose to participate in activities despite their pain and fatigue, doing so often resulted in increased pain and fatigue as well as mental exhaustion and feelings of disappointment. As a result, disregarding constraints was difficult but remained a common negotiation strategy. Participants in Hensing et al.’s study also negotiated constraints by utilized cognitive methods (i.e. rethinking priorities or desires) and by restructuring or modifying activities so that they could participate (i.e. shortening activities or resting more in-between).

Similarly participants in Finlayson, Impey, Nicolle, and Edwards (1998) study of Multiple Sclerosis also experienced significant constraints resulting directly from their ill health. For these patients, fatigue, pain, weakness, and balance problems limited their ability to perform even basic activities such as going up and down stairs, yard work, housework and maintaining employment. The authors drew on statistics which indicate that nearly 40% of MS patients may be unemployed or retired due to the fatigue caused by their disease while over half require daily personal assistance, 32.9% experience transportation or mobility problems, and 27.4% have difficulty maintaining social obligations (pg. 300). However, Finlayson et al. did not specifically explore individual methods of negotiating constraints, instead their intent was to describe the limitations of MS patients and then argue for increased and diversified occupational health services that could support the ability of these patients to live in a communal setting (i.e. help with light housework, job sharing, flex time, and nutritional counseling).

Finally Jordan et al's. (2000) found that arthritis patients carry a significant constraint burden related to persistent pain and joint immobility. Specifically their data indicated that 45.5% of participants felt that their arthritis pain limited their movement, 43.1% said that it caused them to cut down on errands and daily activities, 33.4% said that it kept them from enjoying leisure and hobbies, and 32.8% said that it kept them from sleeping normally (pg. 145). Curiously very few participants reported that arthritis pain inhibited their ability to socialize with friends and family; however, Jordan et al. addressed finding by suggesting that the nature of their study (quantitative without open-ended questions) may not have been sensitive enough to distinguish participant's varying degrees of difficulty with social roles. As evidence of this study design flaw they cited a large body of research indicating high rates of social life disruption among people with arthritis. The authors also did not spend much time exploring constraints negotiation; instead they focused their efforts on understanding the self-care strategies (medications and exercises) utilized by arthritis patients. As a result, like Hensing et al., Jordan et al. were not able to address the constraints negotiation methods used by patients in chronic pain.

Self-Care

In addition to constraints and constraints negotiation, self-care is another integral part to many peoples' chronic illness experiences. Briefly defined, self-care is the broad scope of measures that a person takes to relieve or treat an illness or condition outside of a medical setting (Andersson, Ejlertsson, Leden & Schersten, 1999). It is the most frequently reported behavioral response to headaches, body aches, fatigue, and colds, and many people solely use self-care measures to treat a variety of symptoms (Stoller, Forster & Portugal, 1993).

Stoller et al. (1993) determined that self-care responses to illness result from a series of three major decisions: First an individual must decide whether or not to seek professional care.

Second, if an individual decides not to seek professional care, or if they decide that professional care alone is not sufficient, that person must then decide whether or not to provide self-care. Last, an individual who does decide to provide self-care must choose a strategy and method. This decision-making process is influenced by coping strategies as well as an individuals' belief in their capacity to provide self-care. In other words, it takes a certain amount of agency to provide self-care. In fact, Stoller et al. suggested that "if a symptom can be alleviated through some lay action, people's sense of mastery may be enhanced and the threat associated with the symptom diminished" (p. 37). As a result, self-care is distinct from alternative care in that alternative care (i.e. acupuncture or homeopathy) involves a professional or outside practitioner whereas self-care is self-administered (Andersson et al., 1999).

What prompts self-care? Previous research (i.e. Andersson et al.; Jordan et al., 2002; Stoller et al., 1993) has indicated that self-care is an especially common complement to traditional medical treatments among patients with chronic pain conditions. For instance Andersson et al.'s study of Swedish patients with chronic pain as well as Jordan et al.'s (2000) study of arthritis both found that the worse the pain, the more likely patients were to use self-care measures. The most commonly used self-care measures in both studies included the application of heat or an increase in rest. Secondary measures included physical activities such as walking, jogging and swimming as well as modifications to working conditions or schedules. Likewise the majority (50.6%) of participants in Jordan et al.'s study indicated that they used physical activities such as swimming as self-care strategies for dealing with chronic arthritis pain although many also relied on rest (67.3%), over-the-counter medications (65.9%), and prescription medications (48.1%) to help alleviate their symptoms. Finally Stoller et al. (1993) found that of the 342 patients in their study with muscle/joint pain, only 10.8% took no action at

all to relieve their symptoms whereas 51.8% self-medicated with or without additional professional intervention, 15.2% self-treated with methods other than medication and did not seek any professional assistance, and 22.2% sought a physician consult with or without additional self-treatment methods. It is particularly striking that only 10.8% of participants completely ignored muscle/joint pain because by contrast, 45.5% of participants took no action when faced with rectal bleeding and 33.2% ignored a runny nose. In fact, of the 26 symptoms examined by Stoller and colleagues only one (constipation) was less likely to be ignored than muscle/joint pain. As a result, their study suggests that patients with Fibromyalgia-type joint/muscle pain may be particularly prone to exploring multiple treatment options including self-care.

Jordan et al.'s (2000) study of self-care measures and chronic pain was able to link the use of self-care measures to patient demographics. Specifically the authors reported that patients with lower educational attainment are more likely to use alternative methods of addressing chronic pain than those with higher educational attainment. In particular lower educational attainment is linked to a higher likelihood of visits to the chiropractor, use of over-the-counter treatments, and use of prayer as a means of relieving chronic pain. In addition to demographic variables, self-care is also more closely linked to certain illness conditions over others. For instance Jordan et al. (2000) cited a body of research which indicates that patients with a diagnosis of Fibromyalgia tend to use self-care modalities more frequently than patients with other types of rheumatic conditions. The authors also noted that sleep disruption was more likely to trigger the use of self-care strategies than disruption in leisure activities or the daily experience of pain. Specifically participants with sleep disruption were four times more likely to

see a physician than those without sleep disruption, and 70% of those with sleep disruption saw a chiropractor in addition to a medical doctor.

Studies by Richardson and Ream (1997) as well as Stoller et al. (1993) were able to link self-care to patients' perceptions about the cause of their symptoms. Richardson and Ream noted that when patients thought of their symptoms as part of a generalized illness (i.e. weakness or fatigue) they engaged in higher levels of self-care activities than patients who believed that their symptoms were caused by a disease (i.e. vomiting or fever). Both studies indicated that if patients interpreted a certain set of symptoms as indicators of a specific disease or an acute condition they were more likely to use medications and consult a doctor than if they believed their symptoms stemmed from an indefinable illness or a chronic, mild, or non-life threatening disease (i.e. arthritis).

Stoller et al. (1993) noted that the frequency and persistence of symptoms as well as the degree to which those symptoms interrupted a person's daily life also determined self-care behaviors. In particular they found that disruptive, persistent and frequent symptoms were treated more aggressively and with a broader range of self-care approaches than were minimally disruptive symptoms or infrequent symptoms. Specific to FMS they found that people almost always perceive joint and muscle pain as serious and as a result they almost always seek some form of treatment to address their pain. This is significant when one considers that FMS causes irresolvable joint and muscle pain and as a result patients may find themselves continually compelled to seek treatment for something that, at present, has no effective treatment.

Leisure-based self-care. As many of the previous examples indicate, leisure and self-care often intersect in that leisure time provides a forum for many self-care activities (Son & Hutchinson, 2009). While many of the self-care activities mentioned in previous sections

involved active leisure activities (i.e. walking, swimming and yoga), passive leisure activities have also been linked to self-care. For instance Bennett, Cordes, Westmoreland, Castro, and Donnelly (2000) found that leisure-based distractions such as watching TV along with psychological modifications such as maintaining a positive and accepting attitude towards illness are common and, more importantly, beneficial parts of a self-care plan. Similarly Reynolds, Vivat and Prior (2008) noted that participation in artistic activities such as drawing and painting were particularly helpful for Chronic Fatigue Syndrome patients. In particular participants who engaged in art activities indicated that doing so helped them tolerate the limits imposed by their illness, improve their self-image, maintain contact with the outside world, and feel more satisfaction with their lives in general. In fact, Son and Hutchinson (2009) asserted that leisure may be one of the few arenas of daily life wherein people are able to “experience *success* in their efforts to take better care of themselves” (p. 27, emphasis original).

However, despite a strong body of evidence indicating that leisure activities are integral and important parts of many patients’ self-care practices, the self-care literature is largely void of the specific mention of leisure as a component of self-care (Kleiber et al., 2008; Son & Hutchinson, 2009). Therefore, contributions to a more holistic body of literature regarding leisure-based self-care may prove particularly useful in understanding the complex relationships among leisure, health and well-being (Son & Hutchinson). In particular, Son and Hutchinson called for a definition of self-care that goes beyond simply addressing the essentials of daily living and instead recognizes the empowering aspects of self-care along with the ability of leisure time to provide a forum for improvement, growth and the alleviation of pain and negative symptoms. For instance, Son and Hutchinson created a conceptual model which asserted that, through leisure-based self-care, patients are actively involved in their own physical, social, and

emotional health. This broader definition includes “the range of behaviors by individuals – as well as families and communities – to maintain, restore or enhance health; prevent disease; and limit illness” (p. 8). This conceptualization allows for the consideration of health resources, both internal and external, along with importance of discussing peoples’ ability to access those resources. Similarly Robinson-Smith et al. (2000) conceptualized self-care as integral with self-efficacy and defined it as a psychological “adaptation” that encompasses “the confidence a person has in his or her ability to perform relevant self-care activities” (p. 460). Many of these conceptualizations have their roots in Orem’s self-care theory, first developed in the 1970’s, which suggests that self-care is a fundamental necessity required by all individuals to maintain their health and well-being (Richardson & Ream, 1997). Within this framework, patients’ agency and active decision-making are paramount to fulfilling self-care responsibilities. This same view of self-care will guide the current study as it allows for an understanding of leisure as a forum for “actively managing and caring for one’s personal health and well-being” (p. 8).

Coping

In addition to providing a venue for actively treating the symptoms of chronic illness, leisure has often been conceptualized as a forum for simply coping with the ramifications of a variety of illness symptoms. However, while previous studies have conceptualized coping as distinct from self-care, in this study, as in Son and Hutchinson’s (2009) conceptualization of leisure-based self-care, coping is an *integral component* of self-care. As Kleiber et al. (2002) noted, “restorative experiences” and “small successes” such as those experienced during leisure activities can help people with chronic illness “facilitate hope and the appreciation of new opportunities” and may also help alleviate depression (p. 224). As a result, “the potential for leisure to generate positive emotion may give it a special role in facilitating effective coping and

adjustment in the wake of a negative life event” (Kleiber et al., p. 224). Moreover, leisure activities also provide people with a source of power and control over their own lives, and as a result leisure activities that are undertaken specifically to cope with stress may be particularly powerful tools for marginalized groups such as people with chronic nonratified illnesses (Iwasaki, 2006). Therefore, while the next sections will examine the coping literature, it is important to note that this particular study conceptualizes coping as part of a self-care process (Son and Hutchinson).

Leisure-based coping. Kleiber et al. (2002) defined coping as “the attempt to lessen physical and/or psychological stress or negative feelings associated with problematic experiences” (p. 223). This process is often linked to leisure as Hutchinson, Loy, Kleiber and Dattilo (2003) explained, “Leisure has been hypothesized to serve as a coping resource by buffering the impact of negative life events through distraction, generating optimism, and enabling individuals to preserve a sense of self” (p. 144). In this way coping is distinct from adjustment in that adjustment is a longer-term process that includes adaptation and acceptance whereas coping refers to ongoing actions that help even well-adjusted people deal with the daily effects of a disease or negative life event (Hutchinson et al.). As a result a person may “come to terms” with a severe accident or illness, but their day-to-day experiences will nevertheless be affected by their accident or illness. As a result, even people who have adjusted to a life change will still need to utilize coping mechanisms to help them through these daily struggles (Hutchinson et al.).

Leisure time may provide a particularly appropriate venue for the sorts of mechanisms that help with these daily struggles. For instance participants in Hutchinson et al.’s (2003) study of traumatic injuries repeatedly indicated that shared activities, or what Iwasaki and Mannell

(2000) called “leisure companionship,” were crucial to ensure that participants’ had good quality of life. These social activities were especially valuable because of their ability to buffer the effects of negative life events while also providing motivation for to continue pursuing other coping strategies. In particular Hutchinson et al. spoke about the four ways that leisure serves as a buffer which were distraction, connection to the past, escape from home/hospital and escape from the effects of disease or disability. As participants in Hutchinson et al.’s study explained, they valued any activity that helped them stay busy, distracted, or helped them remove themselves from their immediate situation. Examples included going to coffee with friends, doing jigsaw puzzles, playing paintball, and fishing because these activities distracted them from their disabilities/illnesses while also motivating them to continue to work towards rebuilding their lives. Moreover, Hutchinson et al. noted that social interaction helped participants develop both feelings of normalcy as well as a sense of belonging.

Kleiber et al.’s (2002) review of leisure coping research also noted that “leisure experiences can aid in coping with induced stress in ways that are self-protective, self-restorative, and, ultimately, personally transformative” (p. 220). The authors stressed the importance of pleasant experiences, such as looking forward to an activity, trip, or visit, because the pleasant experience itself, as well as the anticipation leading up to the pleasant experience, generated feelings of hope, optimism and happiness. These positive emotions provide a break from the work of disability or illness and also provide perspective and generate hope for further positive experiences. Similarly Hutchinson et al. found that participating in favorite activities, particularly following the onset of illness or disability generates hope that one’s identity will not be lost as a result of the illness or disability. Moreover, simply feeling better, emotionally and mentally, is a common outcome of many enjoyable leisure activities and an important element in

an effective coping strategy. As Clint, a participant in Hutchinson et al.'s study noted, "You are still being able to do a lot of things. It is a lot better than giving up. It gives you a purpose to live It makes you feel good about yourself" (p. 152).

Finally, Parry's (2007) study of the role of dragon boat racing in the lives of female breast cancer survivors was able to speak to the interplays among leisure, coping, hope, and a multidimensional conceptualization of health. In particular Parry found that dragon boat racing benefitted participants' social, emotional, physical, spiritual, and mental health. As a result of growing stronger in all of these areas of health, participants became better able to deal with their status as cancer survivors and the toll that had taken on their lives. In fact, most of Parry's participants placed dragon boat racing at the top of their priority list in terms of things they were able to do to stay healthy post-cancer. As a result of her study, Parry asserted that building strength across multiple facets of health provides the foundation for effective long-term coping, and moreover she argued that leisure is an essential component of health and one that should not be overlooked.

Previous conceptualizations of leisure-based coping. As a result of the clear benefits of leisure-based coping, particularly in the realm of health, several leisure researchers have proposed theories and conceptual models linking leisure, health and coping. Initially Coleman and Iso-Ahola's seminal (1993) publication was one of the first to set about framing the roles of leisure in terms of coping and health. In doing so Coleman and Iso-Ahola asserted that leisure essentially created a buffering effect for negative life/health events in that it was able to counteract some of the negative physical, mental and emotional aspects of poor health. Specifically their model described two main functions of leisure as coping mechanism: self-determination dispositions and social support resources. This idea of leisure as a buffer for

negative life events has remained prominent and continues to influence contemporary studies (i.e. Hutchinson et al., 2003; Iwasaki & Mannell, 2002; Kleiber et al., 2002) however it has never been indisputably supported (i.e. Iwasaki & Schneider, 2003).

In addition to describing the benefits of leisure as a coping resource, Iwasaki and Mannell (2000) also provided a framework for understanding the roles of leisure within a coping framework. Their model outlined what they called the hierarchical dimensions of leisure stress-coping, and in particular it differentiated leisure coping beliefs from leisure coping strategies. To do so the model takes into account autonomy, friendships, empowerment, informational support, symptom management, mood enhancement, and other tangible and intangible variables (see Iwasaki & Mannell, 2000, p. 166 for a detailed outline of the model) to suggest that participating in leisure activities in the midst of negative life events may lead to feelings of empowerment, and that empowerment may then encourage further coping behaviors. Additionally the authors asserted that leisure provides people with a psychological time-out, a place to take a breather from stress and reconfirm the positive and vital parts of their identities. This model has remained popular in the literature and is frequently cited (i.e. Iwasaki & Schneider, 2003).

Slightly more recently both Hutchinson et al. (2003) as well as Kleiber et al. (2002) divided coping strategies into emotion-focused and problem-focused. They defined emotion-focused coping as mainly cognitively-based and functioning to help a person change the *meaning* of a situation, but not the *actual circumstances* of that situation. These efforts may include reframing the situation, comparing the situation to a worse possible situation, or simply “looking on the bright side of things” (p. 144). Behaviors linked to emotion-focused coping include exercise, relaxation, meditation, support groups, religion, humor, social contact and even the use of drugs and alcohol. Kleiber et al. (2002) suggested that when a negative event occurs

unexpectedly “coping is more likely to be *emotion-focused*, or *palliative*” because patients are looking primarily for distraction or ways to survive their physical discomfort (p. 224). Emotion-focused coping is particularly relevant to this situation because it helps patients “regulate the emotions associated with the trauma without attempting to change the situation itself” (p. 224).

On the other hand, problem-focused coping is often employed when a person feels that their situation *may be able to be changed*. These efforts work to alter the circumstances causing stress and may include “information or advice-seeking, goal-setting, or selecting and working towards solutions (Hutchinson et al., 2003, p. 144)” as well as “creating structure to one’s day, doing activities intentionally to maintain or improve physical or mental health, or getting out of one’s home to make connections with others in various leisure contexts” (p. 157). Both forms of coping often play a role in a person’s overall coping strategy, and leisure in particular provides a nurturing setting for both types of efforts (Hutchinson et al., 2003). In fact, people may purposefully seek out particular types of leisure activities because they believe that those activities will help them deal with stress or other negative life events (Hutchinson et al.). For instance, a patient with arthritis may seek out yoga as a method of building strength or someone with a back injury may begin swimming not only for the exercise but also because swimming can help build supportive muscles without causing further injury. This may be particularly true in the case of chronic illness. As Hutchinson and colleagues noted, people with chronic illnesses “may encounter challenges to maintaining daily routines; changes in relationships, roles, and physical abilities; perceptions of loss of personal control; pain, discomfort and fatigue; social stigma; and an uncertain future” (p. 145). Some of these challenges may be due to mobility and physical limitations, but others may be due to the ways that people see themselves and how they

perceive others see them. As a result, problem- and emotion-focused coping strategies undertaken during leisure time may help alleviate some of their stress and discomfort.

Finally, and most recently, Kleiber et al. (2008) theorized the existence of several main roles of leisure as a resource for people with illnesses or other negative life events. Specifically they suggested that leisure activities provide a kind of buffer for the negative impacts of events such as chronic illness or injury by providing distraction, generating optimism about the future, and providing “vehicles for personal transformation” (p. 322). As a result, leisure “may not only help people ‘feel better’ in the immediate context of coping with rehabilitation treatments, but may help sustain coping efforts as individuals learn to live with ongoing functional limitations” (p. 323).

However, despite the potential positive impacts of coping, people’s actual ability to cope and the effectiveness of their coping strategies may vary across life roles, demographics, illnesses and psychological states. As Hutchinson et al. (2003) explained, “personal factors (e.g. belief systems, personal history with coping) and environmental factors (e.g. social and economic conditions and resources) influence perceptions of stress and appraisal of one’s ability to cope” (p. 144). However, as Kleiber et al. (2002) noted, while the free time activities of people with chronic illness or significant negative life events “may not be experienced as ‘pure’ leisure (i.e. as self-determined, intrinsically motivated) there is relative freedom in the ability to experience some choice and control, if only to create a temporary separation from the stressors associated with the negative life event” (p. 226). As a result, coping may be an important and yet variable impact in the lives of people with chronic illness. In particular, it may help people “escape the restrictions of their [ill] bodies” and provide “social situations where evidence of their disabilities [is] limited” (p. 226). As Kleiber et al. (2002) stated, “leisure has the power to

restore hope for one's future in spite of dire circumstances" (p. 227). As a result, the current study will provide some evidence of leisure-based coping as part of an overall self-care strategy for people with Fibromyalgia Syndrome.

Sick Role Theory

In addition to understanding how people react to illness on a psychological level (i.e. coping or self-care) it is also important to understand how illness works on a societal level. As a result, sick role theory, developed by Talcott Parsons in the 1950's, will provide both a theoretical framework as well as a sociological lens for this study. Parsons' (1951) sick role, functioning within a structural-functionalist framework, was designed to "explain how social structures deal with the consequences of sickness and illness" (Miczo, 2004, p. 348). At the heart of Parsons' theory is the suggestion that society has four main rules for the behavior of ill individuals: first, a sick person is relieved of some social duties and responsibilities; second, while society does not consider a sick person at fault for being sick, they must nonetheless make an effort to get better; third, the sick person is required to seek medical guidance for recovery and comply with doctor's orders; and fourth, a sick person must recognize that being sick is undesirable and therefore must want to get better so that they can resume their duties and responsibilities in life (Arluke, Kennedy, & Kessler, 1979; Crossley, 1998; Parsons, 1951; Shilling, 2002). As Kubsch and Wichowski (1992) explained, social roles such as the sick role are the set of behavioral expectations for occupants of particular positions. However, it is important to note that people rarely occupy just one social role, instead they often occupy many roles at once although those roles may be sectioned into "primary, secondary and tertiary classifications" (Kubsch & Wichowski, p. 142). As a result, assuming the sick role also means "temporarily relinquishing secondary and tertiary roles" such as roles at work or within the

family (p. 143). In the case of acute illnesses in particular, these shifts in role responsibility as well as each actor's role in the process is clear. People who feel ill are to contact a doctor to legitimize their actions, receive a diagnosis, and begin a compliant course of effective treatment. In these instances, the relationship between doctors and their patients is fairly "functional, predictable, and harmonious" because everyone understands and supports the roles of everyone else (Stewart and Sullivan, 1982, p. 1398).

The impact of sick role theory. Sick role theory was crucial to the development of the sociology of medicine because Parsons was one of the first to suggest that illness is as much socio-cultural as it is physical (Crossley, 1998; Miczo, 2004). As a result, the work of many medical sociologists is directly or indirectly influenced by sick role theory, and therefore many of our academic understandings about the illness process have been shaped by it as well. Butler (1970) noted that,

It was not until the publication of *The Social System* (Parsons, 1951) that a systematic statement of the sociology of illness was propounded, and it is only since that date that the sick role has become widely used as a concept in the analysis of illness states (p. 241).

In fact, sick role theory may be so engendered into the training of some medical sociologists that they neglect to mention the theory at all, even when they are explicitly relying on its core tenants. For instance Garro's (1994) study of Temporomandibular Joint Syndrome (TMJ) never referred to the sick role and yet her work suggested a cultural model for responding to illness which demands that "atypical body experiences be interpreted, drawing on culturally based understandings, as indicating illness," and suggested that,

If a decision is made to seek outside help, the practitioner consulted identifies what is wrong and prescribes [a] treatment to remedy the problem. The [patient then] follows [their] treatment in the hope of restoring the body to health. [As a result,] illness can serve to excuse nonparticipation in work and social activities, especially when [its existence is] confirmed by a healer (p. 777).

Garro's work, as well as the great body of literature that does explicitly build on the sick role, illustrates the pervasiveness and high level of impact this theory has had on modern medical sociology.

In addition to shaping many of the ways that sociologists interpret the illness experience, sick role theory also provides an interesting window into the cultural values that guide society's interpretation of illness behavior. For instance some scholars have drawn parallels between sick role theory and Western Protestant-inspired views of work and illness wherein work is highly regarded and sickness is considered socially dysfunctional (Crossley, 1998). This cultural context is evident in that the final responsibility of a patient, according to sick role theory, is to recognize that being sick is *undesirable* and work towards returning to normal life with all its duties and responsibilities (Arluke et al., 1979; Crossley; Parsons, 1951; Shilling). As Shilling's (2002) explained, although a validated sickness may allow for a break from normal everyday activities, it does create other new responsibilities for the patient. For instance a patient who does not make visible efforts towards recovery may be perceived as lazy or taking advantage of the system, a perception that will result in social ramifications. These ramifications may be particularly relevant to patients who cannot fully achieve the sick role, such as those with FMS who will not recover, often do not receive a firm and quick diagnosis, and have trouble interacting with the medical professionals who serve as the gatekeepers of the sick role.

In addition to the Protestant work ethic, sick role theory also highlights Western cultural norms regarding the mind and body. Until the publication of Merleau-Ponty's (1962) *The Phenomenology of Perception*, medical standards and societal norms were unquestioned in their premise that the mind and body operated separately (mind-body dualism) and as a result experiences of the body were privileged over those of the mind. However, Merleau-Ponty (1962) and others have suggested that the mind and body cannot be separated and that experiences of the mind are no less real than those of the body. Nevertheless, mind-body dualism, and its resultant prioritization of body over mind, persists and sick role theory provides a revealing glimpse into the impacts this dualism has on people's lives. Although a full discussion of the links between FMS and mind-body dualism is beyond the scope of this project, it is important to note that the sick role specifically functions as a method of reinforcing this separation and in doing so highlights the cultural contexts in which people with chronic pain conditions must function. As Glenton (2003) pointed out, when diagnostic tests continue to come up empty, some health professionals may turn to psychological explanations for chronic pain. However, this process often causes frustration for patients who feel that psychological diagnoses are akin to being dismissed and misunderstood. After all, mind-body dualism extends even to the sick role and suggests that mental illness is caused by and must be controlled by the patient whereas physical illness is out the patient's control (Glenton; Segall, 1976). As a result, patients with psychological illnesses have a weakened claim to the sick role. As Segall explained, "the rights and obligations of the sick role apply directly to [patients with] physical conditions, but not to [those with] psychophysical and psychosocial conditions" (p. 163). Therefore, the likelihood that a patient will be able to fully claim access to the sick role "decreases as the social and psychological aspects of the [patient's] condition increase" (p. 163).

To further complicate matters, chronic pain sufferers often feel that psychological complications (i.e. depression, anxiety, and panic attacks) have begun as a result of being in constant pain and therefore they are unable to tease out the mental from the physical aspects of their illness.

Sick role and chronic illness. Despite its role as one of the most prominent health-related theories of the past 70 years, sick role theory has faced specific criticism related to its applicability to chronic conditions such as FMS. Therefore, the following section will both address those criticisms as well as make a case for the importance of understanding chronic pain conditions, and FMS in particular, through the lens of sick role theory.

One of the main critiques of sick role theory is that it is unrepresentative of the experiences of people with chronic illnesses because it was designed to focus on acute, temporary and curable illnesses (Segall, 1976; Stewart & Sullivan, 1983). For instance acutely ill patients will often contact a doctor within a week, obtain a clear professional diagnosis, and begin a successful treatment program which promptly returns them to health. Moreover, in addition to physical improvements, most of these patients experience high levels of social support and understanding from friends and family and are accepted as legitimately sick and genuinely working to get better (Stewart & Sullivan). However, chronic illnesses, especially functional disorders like FMS, result in a more complicated process. Moreover, the expectation that a patient with a chronic illness should succeed in recovering and thereby resume normal functioning is inappropriate (Segall, 1976). Additionally, patients with chronic pain conditions often have vaguely defined symptoms which allow them to remain ambulatory and which lack the incapacitating and visible nature of the kinds of symptoms attributed to more acute conditions (i.e. bleeding from a trauma injury or the use of a wheelchair after a surgery) (Segall). As a result, these vaguer sets of symptoms may result in “definitional disagreements between

afflicted individuals and their relatives and physicians” and patients may experience problems maintaining social relationships (i.e. doctor-patient or patient-significant other) and gaining full access to all steps in the sick role (Stewart & Sullivan). Indeed, the emotional and social impacts of these difficulties may be quite pronounced, and as a result some scholars have suggested that the sick role is an inappropriate method of understanding the illness experiences of patients with chronic conditions.

However, Parsons himself “acknowledged that the dimensions of the sick role were ‘relative to the nature and severity of the illness’” and moreover many scholars believe that the basic societal script for how we treat the ill and how the ill are expected to behave does not change in relation to severity of illness (Segall, 1976, p. 163). In fact, Glenton (2003) claimed that even though people with chronic illness may have a difficult time accessing it, “the sick role concept appears to reflect the social obligations and expectations that are present in the minds of health professionals, colleagues, family members, and [chronic] pain sufferers themselves” (p. 2245). As a result, the “delegitimation and stigma” suffered by people with chronic pain conditions is directly related to “their inability to produce a particular set of both clinical and social characteristics that make up appropriate sickness behaviour and achievement of the sick role” (p. 2245). In other words, although achieving the sick role is innately impossible for people with chronic conditions, they will still hold themselves to the obligations of the sick role and their peers, families and friends will do the same (Arluke, Kennedy & Kessler, 1979; Glenton). As a result, understanding the sick role as it relates to these patients is paramount.

The sick role and FMS. Applying sick role theory to the experiences of people with FMS in particular allows for a deeper understanding of the social, psychological and emotional tolls of their illness. As Glenton (2003) explained, chronic conditions like FMS are sicknesses

you “have to fight to get,” and therefore achieving the sick role is like achieving societal validation of one’s symptoms (p. 2249). Moreover, one of the well-established psychological functions of a firm medical diagnosis is that the patient is given some sense of order or meaning for the illness experience (Madden & Sim, 2006). However, as medical doctors are the only ones who can give a diagnosis and thereby validate a person’s participation in the sick role, FMS patients who “find themselves with illness but without sickness” are forced to inhabit a “liminal space” that comes with negative social consequences (Glenton, p. 2244). In attempts to avoid this liminal state and its’ accompanying social ramifications, FMS patients in particular spend a lot of time seeking out a diagnosis (i.e. validation) and this search may become all consuming (Glenton). As Butler (1970) explained, “the burden of proof is on the individual to demonstrate that he is ‘really’ sick, and the medical profession has a special duty to minimize plausible excuses for the evasion of responsibility” (p. 244). Moreover, due to the vague nature of FMS symptoms, patients often go for some period of time between treatments. These lulls further complicate their access to the sick role as it may appear that they are not making consistent and genuine attempts to improve. As a result, patients may feel concern and even fear about the degree to which their pain is validated and accepted by healthcare professionals, family, and friends (Glenton). Therefore, many patients with chronic illnesses find themselves increasingly dependent on medical professionals as their search for a diagnosis continues and their desire to fully achieving the sick role becomes more acute.

Despite, and in many ways because of the difficulties that people with FMS face in accessing the sick role, the current study will use Parsons’ sick role theory as a framework for understanding the illness narratives of FMS patients. Although I recognize the critiques of sick role theory in relation to chronic illness, I nevertheless agree with Garro (1994) who stated that

“even when actual illness events bear little resemblance to the cultural model [for appropriate illness behavior], the model serves as a backdrop for recognizing and comprehending variation and complexity” (p. 778). In fact, Stewart and Sullivan (1982) even suggested that examining chronic illnesses like FMS through the lens of the sick role will result in more vigorous sociological theories about sickness and health. In doing so they pointed out that traditional sick role research based on acute illness experiences often focuses on the stages of the illness process at which “social consensus and definitional clarity” are likely to exist and that this focus has, in fact, inhibited our ability to understand “the process by which normative consensus [about an individual’s health or illness] is achieved, the role of both physicians and patients in that process, and the consequences of the failure to achieve consensus” (Stewart & Sullivan, p. 1398). As a result, exploring the sick role as it relates to FMS may not only shed light on the frustrations of those with chronic nonratified illnesses, but may also result in a more robust and comprehensive understanding of the impacts of the sick role.

Conclusion

Each of the concepts addressed in this literature review was chosen because of its crucial links to Fibromyalgia, sick role theory, and leisure. In the end, sick role theory was framed as a societal script outlining the expected behaviors of the ill with a clear set of steps. In contrast, my earlier exploration of the common symptoms of Fibromyalgia, as well as research outlining the typical treatment experiences of Fibromyalgia patients, drew attention to the specific aspects of FMS that do not mesh with sick role theory expectations. Moreover, framing Fibromyalgia Syndrome within the larger body of chronic illness drew attention to the difficulty of situating any chronic illness, not just Fibromyalgia, within the sick role model and also illustrated the consistency with which patients and their families, coworkers and friends nevertheless expect a

chronic illness experience to mimic the steps of the sick role. The further addition of self-care literature, particularly leisure self-care literature, outlined the tensions between a sick role model (in which care is provided by a physician) and the actual lives of patients with Fibromyalgia Syndrome (who feel compelled to provide self-care if only to supplement the often ineffective treatments prescribed by their doctors) and a brief mention of agency made it clear that some hegemonic tensions are involved in those two choices. Finally leisure-based coping and constraints to leisure were outlined as both issues frequently arise during discussions of the everyday experiences of Fibromyalgia patients. Collectively these various concepts form a framework for understanding the everyday lived experiences of people with Fibromyalgia Syndrome, in particular the confluence of chronic non-ratified illness, sick role theory, and leisure.

Chapter 3 - Methods

Purpose & Research Questions

The main goal of this study was to gather narratives from people with Fibromyalgia Syndrome (FMS) in order to shed light on the sick role within the context of Fibromyalgia Syndrome. Secondary goals included understanding the relationships among self-care, constraints and leisure for people with nonratified chronic illness. To explore these questions I conducted focus groups, in-person interviews and phone interviews with a total of 28 people who had been diagnosed with Fibromyalgia Syndrome. I wanted to understand participants' negotiations of the sick role because much of the literature suggests that these negotiations are problematic processes for people with chronic illnesses. Additionally, I wanted to explore whether leisure activities played a role, positively or negatively, in Fibromyalgia patients' negotiation of the sick role. Secondly, I wanted to understand the potential roles of leisure generally in the overall illness experiences of people with Fibromyalgia. After conducting a literature review on the topic I chose to focus these questions specifically on leisure-based self-care and constraints to leisure because little is known about these concepts in relation to chronic illness. As a result, the set of research questions that guided this study were:

1. Do the narratives of patients with FMS reflect the influence of the sick role? If so, how?
 - a. If so, do their narratives indicate that they are able to fulfill their obligations under the sick role?
 - b. How does their successful or unsuccessful negotiation of the sick role influence their daily lives?
2. Are leisure-based self-care practices utilized by participants in this study?

- a. If so, what types of leisure-based self-care practices, including coping mechanisms, are used?
 - b. If so, what are the effects of these practices on the daily lives of participants?
3. Do participants in this study experience constraints, particularly leisure-based constraints, as a result of Fibromyalgia Syndrome? If so, how are these constraints negotiated, if at all?

Recruitment

The participants in this study were recruited in different ways. Initially I searched national online Fibromyalgia support groups to find the names of support groups in the Champaign-Urbana area. This effort resulted in the identification of three local groups located in Urbana, Mahomet, and Mattoon, Illinois, each of which was affiliated with the regional Arthritis Foundation. I attempted to contact all three group leaders, but only the Urbana group leader, Penny, returned my phone calls and emails and was enthusiastic about the project. It later became unclear as to whether the other groups were still in existence.

After explaining the project, I asked Penny (not her real name) to help me narrow down dates, times and locations for holding focus groups. She guided me towards evening groups on weeknights, and together we determined that public libraries would provide familiar meeting sites that were not on the turf of any organization or association. Penny then contacted people she knew, including support group members and mentioned the project at her Arthritis Foundation Board meeting. She asked people if they were willing to participate in a focus group exploring the experiences of people with Fibromyalgia Syndrome. Any potential participants who were uncomfortable participating in a focus group or whose schedules did not allow it were asked if they could participate in a face-to-face or phone interview covering similar material.

This initial recruitment effort resulted in approximately 10 potential participants, about half of whom participated in one focus group and a few others who participated in interviews during the fall of 2009.

Simultaneous to these recruitment efforts, and at the suggestion of both Penny and my dissertation committee, I utilized the University of Illinois Champaign-Urbana's (UIUC) E-Week email service to recruit participants. E-Week is a weekly emailed summary of campus news and events that is sent to all UIUC system faculty and staff. This effort yielded the majority of participants. About 30 people contacted me as a result of viewing the E-Week announcement. However, it is important to note that not everyone who responded to the E-Week was a faculty or staff member of the UIUC system. Instead, my announcement was often forwarded by UIUC faculty and staff to friends and family members who had Fibromyalgia. Therefore, while I was concerned that targeting the faculty and staff of the UIUC may not provide the most diverse sample of participants, I was encouraged when I began receiving responses from people outside the UIUC system.

The Interview Guide

In order to address my research questions I created an interview guide (Appendix A) based on my review of the literature (Lonardi, 2007; Patton, 1990). However, due to the semi-structured nature of the interviews, discussion was not limited to the questions listed on the guide. Instead the discussions were able to reflect the priorities and experiences of the participants. As a result, each focus group was both a unique research event but also covered similar material to other focus groups. Moreover, as I relied on grounded theory to collect and analyze data, I utilized constant comparison throughout the collection process so that each interview or focus group was shaped by the one that came before it (Glaser & Strauss, 1967).

Specifically, constant comparison method meant that I transcribed and analyzed interviews and focus groups during the same time period as I conducted new interviews and focus groups. As a result, the interview guide was a living document that I constantly changed, tweaked and updated. However, the final iterations of the guide focused mainly on the following core topics:

- Diagnosis
- Symptoms
- Treatment(s) including self-care
- Leisure choices
- Leisure constraints
- Social support
- Interactions with medical professionals

In both the focus groups and interviews, I began by asking participants to tell me about their diagnoses. They normally told what amounted to complex stories relating their relationships with family and healthcare providers, their searches to understand their symptoms, and their feelings about their illness experiences. Participants often began by talking about the start of their illness and then detailing the ways their illness progressed and their search for a diagnosis that may lead to some physical and social relief. These “open-ended biographic stories” often provided scaffolding for the rest of the session as details and supporting elements were added to the narrative as time went on (Lonardi, 2007). As a result, what emerged was a set of stories which often suggested causality and coherence within the FMS experience (Garro, 1994). This scaffolding, as well as some of the more specific details from each story, is what formed the basis for the synthesis stories presented in the following chapter.

Keeping a research diary. Throughout the data collection process I kept a research diary which I wrote in almost daily during the time that I scheduled and conducted focus groups and interviews. This diary not only aided me in the use of constant comparison methods by providing a forum for thinking about narratives I heard each day, but it also provided me with a space for reflecting on the study in general as well as the ways that the study impacted me on a personal level. For instance, on November 10th I wrote, “I have my first focus group today. I have been transcribing interviews [in the meantime]. It’s difficult because the people I talk to are really suffering.” Another entry dated November 14th reads,

The data collection for this project has been stressful for me and has altered *my* leisure – I’ve done a lot more cuddling with [my son], watching comedy on TV, going for hard runs, drinking wine, and eating chocolate than I normally would. I am learning a lot of really interesting things but [it can be] difficult to talk to the people who are really affected by Fibro.

This entry also illustrates the shifts I underwent as I began to be more involved in the lives of people with Fibromyalgia. While at the onset of the study I referred to Fibromyalgia as “FMS” or “Fibromyalgia,” as the study continued I began to pick up on the participant’s lexicons for describing their illness. As a result, “Fibromyalgia” became “Fibro” and “flare” or “flare up” came to describe the times that someone’s Fibro symptoms are particularly acute. These word choices crept into my research diary, daily vocabulary, and into the way I crafted representative narratives about the Fibromyalgia experience.

Data Collection Methods

The data collection for this project consisted of three methods of data collection which occurred simultaneously and involved people who had either been officially diagnosed or, more

rarely, had self-diagnosed with Fibromyalgia Syndrome. I conducted two focus groups in November 2008 which lasted approximately 90 minutes each. Both groups, consisting of 6 and 8 participants respectively, were held at local public libraries in meeting rooms reserved for community use. I chose these locations for their accessibility, familiarity to people in the community, and because they were not associated with one way of thinking about or treating Fibromyalgia (i.e. meeting at a hospital or at a yoga center). The focus groups were audio recorded and I transcribed them myself as another method of gaining familiarity with the data.

I chose focus groups because, as Dodson, Piatelli and Schmalzbauer (2007) stated, “The risk of speaking diminishes in a group dynamic” (p. 838). As a result, I believed focus groups could be useful in providing a power-sharing method of data collection. Moreover, although some participants may speak more than others, focus groups generally provide an atmosphere for collaboration where participants ultimately decide what to tell researchers, how, and in what form (Dodson et al.). Specifically, I agreed with Dodson et al. that while researchers “may facilitate [the focus group] process, it is a group dynamic that moves the [focus group] along, going deep into one discussion and skimming over the next” (p. 838). I felt that this particular format would result in the creation of many representative narratives as participants would reinforce some aspects of each other’s stories and find disagreement with other parts. Like Dodson et al., I noticed that a group dynamic guided certain parts of the discussions in the focus groups in ways that helped to steer my questions towards topics that were particularly important to participants. For example, focus groups engaged in a lot of what I came to call “doc talk” and “technical talk” where participants compared notes on specific doctors and their approaches to Fibromyalgia, or compared dosages and usages of specific medications. While this kind of talk occurred in the interviews as well, it was much more pronounced in the focus groups because of

the group nature of the conversation. As a result, focus group participants may have a bit more control over the breadth and depth of the topics covered than would interview participants.

Limitations of focus groups. Due to these potential benefits of using focus groups, I originally intended to have the majority of participants attend focus groups and then hold mostly face-to-face or a few phone interviews for the minority of people who would not be able to attend the groups. However, at the end of data collection I had just as many in-person and phone interview participants (3 and 11, respectively) as I did focus group participants (14) for a total of 28 participants. In each case participants were able to freely choose the method of participation that best suited their mobility, interests, and schedules. Through this process it became apparent that focus groups are inherently unappealing to certain people for a variety of reasons including shyness, mobility and work schedules. Moreover, even if focus groups are theoretically more democratic than other methods of participation, some potential participants may end up being silenced because their experiences do not fit the norm or because they simply do not feel comfortable speaking in a group setting. As Dodson et al. (2007) suggested, group dynamics often guide the pace, content and form of discussions during focus groups, but this means that minority viewpoints may be downplayed, ignored or not given as much time for discussion as majority viewpoints. This occurred in one focus group that was composed of 5 women and 1 man, especially when the discussion turned towards sex differences and discussions of traditionally female undertakings such as shopping or caregiving. While the male participant in the group did speak, at times he seemed silenced, either self-silenced or indirectly silenced, by the majority female participants since he could not contribute to some aspects of the discussion. While this may have been a result of his personality in tandem with his sex, he was by far the quietest focus group participant in that group and I was left to wonder if he would have been

more vocal in an interview. Therefore, I came to believe that focus groups may offer the most protection to participants when they are from a largely homogenous group; however, they may silence or marginalize participants who are not like the others. On a more basic level several potential participants I spoke with simply expressed their dislike in participating in groups and instead specifically asked to participate in face-to-face or phone interviews so that they could avoid a group setting. This choice was likely made for a number of reasons, but nevertheless it suggests that studies relying solely on focus groups may alienate potential participants and as a result silence a number of voices in the research process.

Individual interviews. As a result of the limitations discussed above, I conducted individual interviews in addition to focus groups. These interviews were supported by a semi-structured interview guide approach (Patton, 1990) using the same guide(s) that were used with the focus groups. However, despite my use of guides, each interview was not only unique from the others but also allowed space for the discussion of topics and issues that were important to the individual participants. Moreover, as with the focus groups, I continuously transcribed and processed the interviews even as I was conducting additional interviews.

Like the focus groups, interviews were conducted beginning in November of 2008. In person interviews (n = 3) were held at a location chosen by the participants according to their comfort and schedules. Specifically, one interview was held at a campus coffee shop and two at a local public library. Telephone interviews (n = 11) were the most popular method chosen by interview participants. Phone interviews were held on the date and at the time of the interviewees' choosing and typically occurred during participants' lunch hours or after 6pm. Phone interviews seemed to be the method of choice specifically for participants who worked full-time 9-5 jobs, participants who lived more than 15 miles away, or participants with limited

mobility as a result of their health. Winter weather conditions may also have contributed to participant's preference for telephone interviews, particularly those participants with limited mobility or limited transportation options. Both phone and in-person interviews were audio recorded and lasted an average of 45 minutes. As in the case of the focus groups, I transcribed each interview myself to ensure my maximum familiarity with the data.

Participant Characteristics

As is the case with Fibromyalgia Syndrome diagnoses, the sample (n = 28) heavily favored women (26 participants) over men (2 participants). To understand more about the demographics of the participants, I asked each of them to voluntarily complete an anonymous demographic questionnaire which could be returned to me in person, by email, or by post. Of the 28 participants, 24 completed and returned questionnaires. As a result, I am able to speak about the demographic characteristics of the majority of participants.

The average age of respondents was 55 years, and all classified themselves as White Non-Hispanic although two also indicated Native American ancestry in addition to White. The majority of respondents (22) indicated that they had been born in the United States although two were born abroad and later immigrated (one Polish participant who has lived in the States for 39 years and one Austrian participant who has lived in the States for 58 years). Respondents had various levels of formal education although they tended to be fairly well educated overall. Specifically, one respondent had a high school education, nine had completed some college, three had Associates degrees, two had Bachelor's degrees and nine had completed graduate or professional degrees.

When I asked respondents about their employment status I found that the majority worked full time (11) and seven were retired. However, there were also several respondents who

could not work full-time, specifically two were unemployed not by choice (one of those due to cancer treatment) and three were on disability. On a related note, the majority of participants earned incomes at or above the 2006 national average of \$58,029 (Johnston, 2008). Specifically five indicated household earnings of over \$100,000, six indicated earnings of \$75,000-\$99,999 and six earnings of \$50,000-\$74,999. The remaining four were split between earnings of \$25,000-\$49,999 or earnings of \$0-\$24,999 per year. Three respondents chose not to answer this question.

In regards to marital status, the vast majority of respondents (19) indicated that they were married at the time of participation while four were divorced and one was living with a partner. Participants in the study often talked about their grown children during interviews and focus groups; however only two out of the 24 respondents to the questionnaire actually still had young children living at home.

As part of the questionnaire I also asked respondents to estimate the number of years that they had been experiencing symptoms of Fibromyalgia Syndrome. Their responses were striking in that the vast majority indicated living with Fibro symptoms for many years (between 3 and 56 with an average of 30 years). Of these, only one respondent indicated that she has been cured of Fibromyalgia, and she indicated that this occurred after 10 years of experiencing symptoms.

Finally, I asked respondents to indicate any other chronic illnesses that they experience in addition to Fibromyalgia because of research FMS often co-occurs with other illnesses. The results were striking in that 20 of the 24 respondents indicated experiencing additional chronic illnesses. Only three said that they did not experience any illnesses aside from FMS. One respondent indicated that she would rather not answer the question. Of the co-occurring conditions listed by respondents, the most common were some form of arthritis (7), some form

of spine or back problem (7), or Irritable Bowel Syndrome (7). This was followed by high blood pressure (6) and hypothyroidism (5). Other conditions listed one to two times included bladder/urinary problems, cancer, allergies, and sleep disorders along with other kinds of functional disorders like Restless Leg Syndrome or Chronic Fatigue Syndrome. In fact, most respondents listed more than one co-occurring chronic illness in addition to FMS. Many participants discussed depression during the interviews or focus groups but only two respondents listed depression as a co-occurring condition on their demographic questionnaire.

Interactions with Participants

Although I made final decisions regarding the presentation of findings, study design and data analysis, I did involve participants in various ways throughout the research process. As Dodson et al. (2007) stated,

It is precisely the acts of asking for and believing in the wisdom of others and acknowledging and demonstrating our knowledge limitations that open the possibility for others to make the commitment of a critical analysis and make meaning with us (p. 840).

As a result, my collaborative efforts during this project began in the planning stages when I solicited Penny's help in recruiting other participants as well as choosing a time, day and location for the focus groups. It was also, in part, Penny's suggestion that led to my use of the E-Week listserv and subsequently the majority of my research participants. Participants also helped me revise my interview guide not only indirectly by participating in a research process focused on grounded theory methods, but also directly by telling me how my words or questions sounded to them. In one specific instance I received a phone call from a woman who had been forwarded the E-Week bulletin containing information about my study. She introduced herself as Lynn Homan and said that she was concerned about my description of the study, particularly

my use of the phrase “leisure activities,” because she felt that the word “leisure” gave credence to popular notions that people with Fibromyalgia Syndrome are lazy, making it up, or not really sick. She told me that she had forwarded my email on to friend and fellow FMS patient, Audrey Driscoll, who had agreed that my language was offensive. However, Lynn and Audrey had a solution. They suggested that instead of “leisure” I use the phrase “quality of life activities.” After a discussion about various phrasings, and after explaining what I meant by leisure, I agreed with Audrey and Lynn and changed the phrasing on all new promotional materials as well as adjusted the interview guide to say “quality of life activities” instead of “leisure activities.” In the end Lynn and Audrey became participants in the study and continued to provide keen insights into the lives of people with Fibromyalgia.

Reading transcripts. After completing the focus groups and interviews I gave all participants a chance to review the transcripts of their focus group/interview. In the case of the focus group I replaced the names of participants with numbers before distributing transcripts so that neither real names nor stage names could be discerned by fellow focus group members. In the case of interview transcripts I did not change any information before sending them to participants.

The majority of participants returned comments or edits in some form, and in most instances they made minor edits involving sentence structure or word choice so that their speech was clearer. In many instances participants were also self-conscious about how they felt they had presented themselves. For example, the only participant who I knew before the study wrote,

Megs - Great transcription. I sound like an idiot. It's fine w/me if you put in "[identifying characteristic]". I have no problem with it. Page 13 should read Vitamin C 6,000 mg. not Vitamin B. It's C Diff or clostridium difficile (if you want to look it up) and the

machine is the Bicom. <http://www.drhemerson.com/bicom2000.htm>. Sorry it took so long to get back to you...I've been slow on getting caught up from vacation e-mails (and I have a stomach bug. Gross!)

Similarly a focus group participant said,

Hi Megan,

I hope you had a wonderful Thanksgiving! My discussion number is 7. Here are my comments on the transcript. Page 1 is fine. Page 11 is fine. Page 17 please erase the first quote – not sure what I was trying to say ☺ I didn't realize that I say “you know” so much. SORRY!!! I revised it a little.

Other participants read their transcripts and benefited from doing so, but did not necessarily have any edits. For example one interview participant wrote,

Hi Megan,

I just sat here, read the entire transcript and concluded two things - first, you asked great questions and secondly, while my answers may not help anyone else they added huge clarity for me. You helped me put my feelings about having fibromyalgia into written perspective, something I've never done. If need be I can turn to this transcript and reread it for motivation during the bad times. Despite my rambling on (and on!), I was pleased to be able to verbally walk through the process again and see it evolve into what I consider a generally positive place for me to be. The interview with you was more like having a chat with a friend, you made confiding in you so comfortable.

Similarly a focus group participant said, “Thanks for sharing and getting us together. I did not realize how much talking to other people with Fibro helped. Keep up the crusade!”

Despite the largely positive reactions of many participants, one participant did have a negative experience reading her transcript. This participant was concerned because she felt that she did not sound coherent. She was worried that her perceived lack of articulation would negatively impact the project and asked if she should leave the study. I explained that leaving was her choice and encouraged her to feel free to make any decision she wanted. She ended up staying in the study but as a result of her concerns I did look closely at her transcript. Despite her worry, I did not find her speech patterns any different than the speech patterns of other participants. However, I think her story is indicative of the fact that many people are not aware of how free form speech can be and therefore may be alarmed when they read a verbatim transcript that does not sound the way they write. It may be that we as researchers need to do a better job of preparing people for reading transcripts and be more cognizant of the potentially stressful impacts of involving participants in various aspects of research.

Representing My Findings

The purpose of my study along with my research ethics and values led me to choose particular theoretical frameworks and certain qualitative methodologies to collect data; however, when it came time to choose the format for presenting results, I was faced with a vast array of tools within the qualitative toolbox. Moreover, I was well aware of what Denzin and Lincoln (2005) call the “crisis of representation,” in other words, the idea that by choosing how to represent our findings we as researchers are privileging certain forms of knowledge, and certain aspects of knowledge, over others. Although this crisis on some level is largely unavoidable, I nevertheless felt that it was important to be attuned to the ways that participants presented knowledge themselves and take my cue from their methods.

Choosing a research format. Keeping a research diary also helped me choose how to represent my findings. In particular I noticed that I was primarily jotting down repeating narrative elements and I also wrote that many participants, particularly in the focus groups, engaged in a sort of storytelling when it came to describing how they came to be diagnosed with Fibromyalgia. Just as researchers focusing on sexuality write about the prevalence of shared narrative elements in “coming out” stories (i.e. Penelope & Wolf, 1989), I too found shared narrative elements in the diagnosis stories of people with FMS. As a result, I decided to represent the results with a sample story drawn from the experiences of many participants and highlighting the shared elements of their stories. My goal in choosing this format was to reflect both my experiences understanding the data as well as the ways that participants chose to communicate their experiences to me.

Involving others. As a result of reading the transcripts and, as Bernard (2000) would say, “pawing” the data, I developed a basic conceptualization of common narrative elements as well as the idea of presenting the results in narrative form. However, as I noted previously, researchers are influenced by a variety of sources when they go about the process of shaping the data and as a result it can be helpful to seek the input of others. As Ryan and Bernard (2003) noted, there is no ultimate validity in any research product but we can strive to maximize the clarity and agreement of our assertions. One way of doing this is to ask others for their help and judgment.

For this study in particular I asked for input from the study participants themselves by emailing each participant a three page list of what I felt to be their shared narrative elements and asked for comments, edits and suggestions. All of the participants who responded said that these

elements accurately represented their experiences with Fibromyalgia, and many added that they were eager to read the completed document. For instance one participant responded,

I don't have as much experience w/Fibro as many people, but I think you nailed it. I read the doc, then thought, then went back and read it again. Every time I thought of something I thought wasn't included, I realized it was in another section. You nailed it. I can't wait to read your dissertation!!!!!!!!!!!!!!!!!!!!!! I would also like to see your results published in a regular magazine, not just an academic journal. I think it'll probably be of benefit to many people.

KEEP UP THE GOOD WORK!!!!!!!!!!!!!!!!!!!!!!

While another said, “Good job of pulling out all of the points we talked about. The outline is like I wrote it about myself. A lot of my thoughts. Thanks for all your efforts.”

Another simply replied, “Thanks. I’m anxious to read the study.”

A Narrative Approach

Due to the narrative quality of many of the interviews and focus groups, I chose to utilize narrative analysis as the primary mechanism for working through the data. As Franzosi (1998) explained, narrative analyses are vital to understanding sociological phenomena because they “shift sociologists’ concerns away from variables to actors, away from regression-based statistical models to networks, and away from a variable-based conception of causality to narrative sequences” (p. 526). It was exactly this sort of approach that I hoped to achieve, not only to fill a gap in the literature but also to remain true to the ways that participants themselves presented their experiences.

Narratives may be defined in several ways and, as Franzosi (1998) suggested, are ever-present in contexts ranging from painting to conversations. Narratives tend to be systematic,

structured into a beginning, middle and end, and often suggested a framework for a series of events. Within the research context narratives may be told all at once, as in one response to a particular interview question, or they may be spaced out throughout the interview as the participant slowly builds on his or her framework. For the purposes of this study, narratives will be conceptualized as verbal sequences of events occurring either all at once or over the course of the research event which lead from one situation to the next and provide some type of structure for the events they describe (Franzosi, 1998).

Illness narratives. Understanding illness narratives specifically within the case of complex illness processes like FMS is useful because narratives are innately employed to link complex concepts such as leisure and the sick role, and are often “shaped by social context and informed by cultural knowledge” (Garro, 1994, p. 775). These characteristics are particularly relevant to the study of sociological theories such as the sick role because, as Garro noted, “in reconstructing their narratives, persons situate or contrast their individualized accounts within broader cultural models and other shared models” (p. 776). In other words, we often include our reactions to social norms in our narratives (Garro). Moreover, people with FMS often struggle to reconcile their past and present in cohesive ways, and illness narratives may help them do so because narrative creation inherently requires a structure, normally involving timelines and causality (Werner et al., 2004) These structural interpretations of events provide insight into the ramifications of the FMS experience. In particular illness narratives have a unique ability to provide rich and nuanced views of the complex social and psychological processes surrounding health, and therefore narrative analysis has gained a strong foothold in the study of chronic illness (Robinson, 1990; Werner et al., 2004).

Narratives as representations. Despite the many potential benefits of narrative analysis, narratives themselves can be problematic in that all narratives are, by definition, constructed and therefore they reflect only what narrators themselves judge worthy of discussion (Garro, 1994; Werner et al.). Therefore, the narratives collected during this project may be best thought of as “self-idealized version[s]” created for an audience that, as I initially explained to the participants, would not only include me but also doctors, healthcare workers, academics and the general public (Werner et al.). As a result, the synthesized stories I present in the following chapter are in actuality idealized stories into which order, causality and a certain amount of polish have been added. This in no way means that the stories are any more or less real, it merely serves to indicate that they are socially created events reliant upon storytellers and intended audiences. Therefore, the stories I present later are able to speak just as much to the social positioning of participants as they do to the actual events occurring in participants’ lives.

Analyzing the Data

The end result of my data analysis included the delineation of a set of themes as well as the creation of a set of synthesis stories. Both aspects of data representation were constructed from the words and narratives of the 28 participants in this project.

Identifying themes. I began the overall analysis process by examining each interview and focus group independently (horizontal analysis) to explore individual themes and narrative elements and then examined the transcripts in relation to each other (vertical analysis) in order to identify shared themes and narrative elements (Lonardi, 2007; Werner et al., 2004). As a result, certain themes came to my attention, namely because participants would use common words or phrases to describe certain key ideas. As Ryan and Bernard (2003) noted, repetition is one of the easiest ways of identifying important aspects (or themes) in participant’s lives. For instance

many participants in this study talked about being misunderstood and often used phrases such as “people on the outside just can’t understand” or “my family never really did understand.” I noticed the repetition of these phrases and ideas as I read and re-read the transcripts, and as a result I shaped a theme around the idea of being socially misunderstood. I recognized other themes in a similar manner, and once I had a complete list I read and re-read that list to ensure that each theme was distinct enough to stand on its own and also was not too closely linked to any other theme. I also wanted to focus specifically on themes that related to my original research questions, and so I chose to highlight those most related to the sick role, self-care, and constraints.

The grounding of this project in leisure studies and the resulting questions that I asked during focus groups and interviews also shaped the themes that emerged from the data. Although it is likely that participants would have spoken in some fashion about the activities they choose to do, want to do or cannot do during their free time, even if I had not specifically asked about leisure, it is perhaps less likely that as much of the conversations would have centered on leisure had I not guided them in that direction. As a result, my construction of the leisure-related themes was complex in that while these themes did emerge from the data, the original impetus to talk about leisure often came from the questions in the interview guide. Moreover, my pre-existing knowledge of and grounding in leisure studies concepts further shaped the ways that I interpreted leisure-based themes once they had emerged from the data.

Creating stories. Although I felt that identifying themes was an important aspect of data analysis, I also wanted to reflect the narrative nature of so many of the interviews and focus groups. As a result, I chose to create a group of synthesis stories to provide context and texture for the themes I had identified as well as to represent the feel of the focus groups and interviews.

The main purpose of the synthesis stories was to tell a meta-story that could not be portrayed simply by representing one theme or another. As a result, these stories are designed to speak to broad concepts such as leisure-based self-care and the impact of the sick role.

I began creating the synthesis stories by thinking about different ways to combine key themes with particularly memorable events that arose during the data collection process such as Penny's discussion of the polio scares, Joanna Donne's discussion of her children's kidnapping, and DJ's focus on balance. To do so I created characters who encompassed many participants. I thought about the characteristics that most, if not all, characters needed to share if they were to represent participants in this study. Those characteristics were namely middle-age, female gender, feelings of frustration, and an often unsuccessful but consuming search for a diagnosis/cure. Then I considered the ways that, despite these significant similarities, participants differed from each other and I tried to honor those differences in the characters that I developed. For instance I based the character of John Thomas on the two men in the study, and in particular I tried to make John Thomas' word use and vocabulary mimic what I noticed in the transcripts. Specifically, both men spoke frequently, and much more often than the women, about not wanting to burden their families and not wanting to wallow in their pain. The character John Thomas shares those feelings. Similarly the character of Dena Jacobs was based on the older women in the study. These women in particular seemed to have a certain kind of wise perspective about Fibromyalgia and they were more likely to talk about finding balance in life than were younger women or the two men. The character Dena Jacobs talks a lot about balance in her fictional letter to her daughter. Other characters came about in similar ways in that they were based on actual participants but were able to encompass more than just a single participants' voice. Then in addition to character development I incorporated common narrative

phrasings (i.e. the way that many participants listed specific medications, used words like “flare” or “trigger,” and recommended particular doctors) into the stories because I felt that doing so allowed me to present the themes and participants in a richer context.

In the end, the set of stories I present reflect elements from the majority of participants but also include specific chunks of text taken from one particular participant or another. These stories are not completely faithful to any one person’s illness narrative, but instead serve as storied summaries of a collective set of experiences (Werner et al., 2004). I did not create any key concepts in the stories, all the core concepts are representative of real participants, but I did take creative license to, for example, combine elements of two or three people’s stories into one character’s story. This structure works because, as Denzin (1986) asserted, that “every life story is unique, yet representative of every other life story” (Robinson, 1990, p. 1177).

Names. The names that I used in the results chapter were chosen in a variety of ways. The names in the themes section of the results chapter were chosen by participants themselves. Some participants specifically chose a name that was personally meaningful to them, others participants chose names that they liked, but did not indicate that these names had any special meaning beyond preference, and some just chose the first thing that came to mind.

The names in the synthesis stories section were chosen by me and do not carry any particular meaning beyond serving as summary characters for several participants at once. Finally the names given to doctors in the results section were also chosen by me with the intent of protecting the actual names of doctors mentioned by participants over the course of data collection.

Conclusion

The methods and modes of analysis used in this study were specifically designed to both answer particular research questions as well as provide a space for the voices and rich experiences of the participants in the study. In keeping with these goals the following chapter, Chapter 4, will present both the themes and synthesis stories as I described them above and then the concluding chapter, Chapter 5, will link these themes and stories to my original research questions.

Chapter 4 – Findings

This chapter is divided into two primary sections. The first section details a set of themes which were developed as described in Chapter 3. The themes represent the core elements of the transcripts that related most directly to my research questions, specifically:

- The tensions felt by participants with Fibromyalgia who nevertheless want to fulfill their obligations as outlined by the sick role.
- The roles of leisure in the everyday experiences of people with Fibromyalgia Syndrome, especially the leisure-based self-care practices employed by Fibromyalgia patients.
- The role of leisure-based coping in experiences of people with Fibromyalgia.
- The everyday constraints experienced by people with Fibromyalgia and their ways of successfully or unsuccessfully negotiating those constraints.

As a result, this set of themes should not be read as an exhaustive list, but instead as a selection of key themes that are able to most clearly address my research questions. In addition this section provides a space for the literal words of the participants and as such creates scaffolding for understanding the synthesis stories that follow.

This second section consists of a set of synthesis stories which were created as described in Chapter 3. The stories in this section provide context for the themes presented earlier, and also allow the reader to experience full and uninterrupted examples of the sorts of narratives that emerged during the data collection process. These stories also serve to illustrate the linkages among my initial research questions (i.e. the links between unsuccessful sick role negotiation and leisure-based self-care). As a result, the chapter as a whole ensures that the results of this study speak directly to my original research questions while also including the voices of the researched and illuminating the linkages among key concepts and research questions.

Themes

I identified the following set of 6 themes after examining each interview and focus group independently (horizontal analysis) and then examined the transcripts in relation to each other (vertical analysis) (Lonardi, 2007; Werner et al., 2004). The following themes came to my attention namely because participants would use common words or phrases to describe certain key ideas. As Ryan and Bernard (2003) noted, repetition is one of the easiest ways of identifying important aspects (or themes) in participant's lives. I also wanted to focus specifically on themes that related to my original research questions, and so in crafting these 6 themes I chose to highlight those most related to the sick role, leisure-based self-care, leisure-based coping, and constraints. As a result, the 6 themes that will follow are: "The difficult search for a diagnosis;" "Most people don't understand;" "Caring for self through leisure;" "Coping through leisure;" "It's all about choices;" and "All this stuff I used to do." I will begin by discussing "The difficult search for a diagnosis."

The difficult search for a diagnosis. One of the most universal themes that emerged from the focus group and interview transcripts was the strong desire for a meaningful and actionable diagnosis. While almost all participants began their inquiry for a diagnosis with a routine doctor's visit, for many this initial visit was only the beginning of a long and often frustrating process. The following exchange from one of the focus groups illustrates participants' determination to receive a diagnosis as well as their difficulties in doing so. Monica, a middle aged married woman who works part-time at her family business begins by explaining her diagnosis process. Later Zoe, an energetic middle-aged married woman who was exceptionally knowledgeable about the medications used to treat Fibro, joins in.

Monica: I have stomach ulcers so they checked my stomach and then I had Irritable Bowel Syndrome [Others: Mmhmm] so they checked all that and then I had something else and so it was a process of elimination, I had all these things and then when they finally said, ‘We think you have Fibro’ and I looked it up it’s like, ‘Oh, all these people, these are symptoms of Fibro! All along!’”

Voice: -Stacking them all up-

Monica: -Yeah, they just can’t put it all together.

Zoe: Well it takes a long time to diagnose it-

Monica: Yeah, it really did-

Zoe: You need to continually have these symptoms for a long time. Rule out this, rule out that. I was kind of, and I know this sounds stupid, but when I found out it was *just* Fibro [Others: Mmhmm; Yeah; laughter] ...because, you know, I began to think I had MS or something.

[Others: Mmhmm; I did too; Mmhmm]

Zoe: -and I didn’t want to say anything and I kept thinking about it and...this stupid Internet doesn’t help any!

Voice: Oh I know!

[Voices overlap for less than a second]

Zoe: Finally after I just kept complaining every time I went in, and I told [my doctor] I ought to have buns of steel as bad as they hurt [laughter], he started looking through my chart and he said, “Well you consistently [have these symptoms],” and [then he started explaining that I had Fibro].

Monica's experience was not unusual. As Aimee, a French immigrant and graduate student who first experienced FMS in her late adolescence explained,

Aimee: I was experiencing symptoms before I was diagnosed but I just trusted the doctors, "Oh well they say it's due to my panic attacks, okay." I trusted that doctors would tell you the truth. I didn't have the Internet at home and I did not, I just, I just trusted the doctors until it became so bad, so badly nasty on my body.

This link between trust and diagnosis was echoed by Niki Blackstone, a fervent follower of homeopathic medicine, who explained,

I did not go to a traditional Western doctor for many reasons. One, I've been misdiagnosed for so many years for other problems that I don't trust them. Second, in order to diagnose Fibromyalgia they send you through this mountain of tests. I mean they don't really, you know this from your reading, they don't have a way to diagnose it. And their protocol is, "Here are pills, live with it." And you have to go three months or more feeling like this, and all this other stuff, and I thought, "I'm not doing this." My intention is to get rid of this, not to learn to live with it, and both [homeopathic] doctors [I visit] have assured me that this is temporary. Now I think they're right.

As the above examples illustrated, most, if not all, participants were only diagnosed after years of visits to different doctors and scores of inconclusive diagnostic tests. As John Brennan explained,

[My diagnosis] came about after probably 2 or 3 years of ruling everything else out. I had two neurologists; they thought it was MS because I was having neurological symptoms like numbness in my hands and feet. I saw one rheumatologist and he checked me for a standard set of autoimmune diseases because I do have them in my family. And

I'd say I probably saw about 6 or 7 [other] doctors over about a 2 or 3 year period before finally somebody hit upon the diagnosis.

In fact Angela, a mother and avid gardener who had recently gone on disability for her Fibromyalgia, saw so many specialists that she was not even clear exactly when or how she received an FMS diagnosis. She remembered,

Angela: The first diagnosis I got was that I might have Chronic Fatigue Syndrome but the doctor didn't think that exactly fit. At the time evidently I didn't have all the criteria for Fibromyalgia. So I went to two different rheumatologists. The second one, I'd been seeing her for a little while and I was having more difficulty, more pain, more dizziness and one time when I went to see her I said something about that and she said, "Well you're probably having a flare-up of your Fibromyalgia." And I just looked at her and I said, "Is that what I've got? Nobody's ever told me that!" She looked real startled and she started ruffling through my chart and, "Well yeah, that's what I've got!"

Megan: Oh my gosh.

Angela: So, you know it was kind of...a surprise, I guess.

Even once participants did receive a Fibromyalgia diagnosis, many of them still did not feel that their diagnosis actionable in any way that would lead to a resumption of normal life. As DJ, a retired grandmother and ex-military wife who feels that she has had Fibromyalgia from a young age, explained,

DJ: It had been suggested a couple of times over the years that I might have Fibro but I resisted the diagnosis.

Megan: Why?

DJ: (pause). It changes your life. And looking back I've realized how much it had factored in to decisions that I'd made.

Later she explained that a Fibromyalgia diagnosis is difficult because it requires long-term lifestyle changes that, at best, manage the pain. Yet there is no cure or miracle drug to make the pain go away completely. As a result, while she was relieved that her diagnosis was not terminal, she nevertheless hoped for a diagnosis that could lead to a cure.

In addition to struggling with FMS because it cannot be cured, or in many cases even managed well, some participants also spoke about struggling with FMS because of the stigma attached to the illness itself. Billie G., a middle-aged married woman who was on disability as a cancer survivor and had a very relaxed attitude towards FMS acknowledged that, at least in the recent past, Fibro has been considered a “flaky, bizarre condition no one knows anything about.” Similarly Sandy, a middle aged phone interview participant who liked to exercise, had the following exchange with me,

Megan: Did you know anything about Fibromyalgia before your diagnosis?

Sandy: Not much. I think I was part of that group that thought that there was a lot of stigma attached to it. So when they told me that's what I had, I was like, “Ugh! Not good. People are going to think I'm crazy or something!” (She laughs).

Finally Sarah, the only participant in the study who considered herself cured, recalled her past (and in many ways continued) resistance to being labeled with Fibromyalgia. She explained,

Sarah: [The first doctor I saw] sent me [to another doctor, Dr. Swan, who] was treating all the Fibromyalgia cases in town and I told [Dr. Swan], “I don't want to call it Fibromyalgia. I don't want the drugs, don't want all the treatments - just help me.”

Megan: So why didn't you want to call it Fibromyalgia?

Sarah: I don't believe in it as a diagnosis, as a specific diagnosis. I just had pain, but I believe that my pain was a result of some injury and accumulated stuff and [eventually your body gets tired and] you just crash.

However, Dr. Swan believed that Sarah did have FMS and did not want to treat her without drugs and other treatments. They argued and Sarah was referred again, this time to another primary care physician. At this point, however, the diagnosis of "Fibromyalgia" was firmly in her medical records. Sarah eventually found a doctor who helped her craft her own treatment plan, and part of that plan was attending a support group for Fibromyalgia. However, she quickly stopped attending when she learned most of the participants in that support group were Dr. Swan's patients; and moreover, as she grimly added, "None of them were getting better."

As participants' experiences suggested, receive and then living with a Fibromyalgia diagnosis is difficult on many levels and often requires a great deal of work and persistence. This difficulty overflowed into participants' social lives as well.

Most people don't understand. In addition to difficulties related to receiving a diagnosis, many participants also spoke about the social implications of Fibro. For example Sandy was discussing her social obligations when she interrupted herself and said,

It is frustrating because a lot of people don't understand [Fibro]. You look like you should be fine, but you're still in a lot of pain and the fatigue and stuff like that. But when you can't [do things], you know even just like community obligations or clubs you're in or church groups or something like that, they think, 'Well you should be able to do all this.'

DJ, a retired grandmother and interview participant, also had moments where she felt that friends and family did not understand. In particular she remembered a vacation she took with a friend who quickly became frustrated by her Fibromyalgia-related dietary restrictions. DJ recalled,

I could tell by the end of the two weeks she was really tired of my having to take a little longer to make food choices in restaurants, [but] I was really feeling being out of my element. By the end of the first week, I was ready to go home, but we were driving and it was her car so that wasn't going to happen.

She continued, "There are people who understand and there are people who don't and there are people who *say* they understand who don't." Later she added,

I have now stopped making long-term plans because I can be very enthusiastic and excited today about, "Let's go to South Carolina in December" and then December comes and I've just gotten over cystitis, [I'm on an] antibiotic and some other things and it's not such a great idea anymore. And it makes me look, or anybody look, unstable, like you can't be counted on, like there must be something really weird going on. But it's a matter of the symptoms shifting, having bad days when you think it's going to be a good one, knowing that mornings are hard, it gets better in the middle, and then by evening you can be pretty achy again and have some things going on. And I guess it would help if, even if they didn't understand it, if they just were more tolerant, more compassionate, and didn't just blow it off, you know? There's still such a tendency not to take it seriously. I have had to, at different times, remind my children that this isn't something that I've made up. I do understand how it affects my life negatively, but that doesn't make it go away, and that doesn't mean that I'm not going to be irritable about it, or that

I'm not going to have bad days, because you do. I wish I could wake up tomorrow and it would be gone. But it's not going to happen.

As DJ's example illustrates, not only do people with Fibro have trouble getting their friends and even families to understand their illness, and they also have trouble making plans with people because they cannot be sure how they will feel and they do not want to seem as unpredictable as their symptoms are. For instance, Grammy, an older married woman with grown children and a particularly difficult experience with Fibromyalgia explained,

People don't understand the pain that you're in unless you're in a splint, you have crutches, blood dripping out of you, there's an obvious sore or obvious injury. But when you've got things like this - nobody cares! [They say] 'Here, take this 100 pound bag of taters and throw it up the stairs!' (She laughs) and you can't say, 'No, well, it hurts too bad.' They don't care. So unless you wear a sign around you that says, or, I guess in a way I do because I've become a real witch in the last two years. Just alienated myself to the point where, even in church, I used to do so much stuff with church and now I go when I can and [I don't go] other times. Nobody can count on me for anything. I sign up to do things and people look at you and 'Oh thank you' and you know they're saying, 'Yeah right lady.'

As these examples illustrate, participants were acutely aware of the negative social impacts of having an unpredictable and non-ratified illness like Fibromyalgia. Friends and coworkers grew frustrated with the modifications necessary to spend time with people with Fibromyalgia, or they had trouble believing that Fibro was a real condition so it was hard to feel compassion for their friends and relatives. As a result, Fibromyalgia was often socially and emotionally painful in addition to physically uncomfortable.

Caring for self through leisure. As a result of their difficulties finding successful medical treatments for Fibro, virtually all of the participants in this study relied on leisure activities in a utilitarian way to help them manage their symptoms. For instance many participants talked about specialized activities like getting massages or participating in classes like in-water Tai Chi, the Alexander Method, or meditation. They believed that these classes and activities helped them treat their Fibromyalgia symptoms. For example Penny, an older married woman with grown children ran a local support group and whose daughter also has FMS and Johanna Donne, a middle-aged married academic woman who likes to travel with her husband, had the following exchange,

Penny: I tried I-Chi for a while which is Thai Chi in the water, and I found that beneficial but the deterrent to all of these alternative methods is your insurance companies don't pay for them and it gets cost prohibitive.

Megan: A lot of you are nodding.

Johanna: I do go every week and it's every expensive. I'm just lucky that my husband doesn't complain.

As this example also illustrates, most participants could not afford for these classes and services to be part of their everyday routines because insurance often did not cover them. As a result, the types of activities that participants did regularly often did not cost much money. For example, Robin Merriwhether, a middle-aged phone interview participant who was very health-conscious, developed a stretching and exercise routine that she did every night before bed, and during our phone conversation she was able to list from memory at least 10 exercises she does along with the number of times she repeats each exercise. Similarly Billie G., who has FMS but

is on disability due to cancer, said that general physical activity was one of the best ways to treat her Fibro as long as she kept from overdoing it. She explained,

I'm not working anymore, so there goes that activity. I'm a self appointed slack pot and it's very difficult to get myself off of the couch for any reason, even my health, so that's bad on my part. But I find when I [do] get up and just walk around and am mobile and active, that helps. But if I have a day where I'm just feeling a bum or if I've done too much the day before, you know I try to keep getting more active and doing more things, I have more vacuuming, more yard work, anything just trying to get back into shape from all the chemo, and the day after I do anything [to difficult], I feel horrible. So it's hard to motivate myself to get into an exercise program [but] my oncologist has recommended stretching yoga.

Similarly DJ, a grandmother and former military wife, explained with military phrasing that exercise and wellness were “strategic to my wellbeing as a woman, as a mom, and as a grandmom” and that her “biggest fear is what will happen if I can't move anymore.” I asked,

Megan: What exercises have you found that work for you?

DJ: Walking, just walking, because of the weight restrictions-

Megan: -because of your back?

DJ: Yeah, I can't bend [my back or my] neck and my spine's deteriorating from the surgery that I had so I'm restricted on lifting. But I can walk. And every day that I can get out and walk is a good day. I feel better when I get out and walk than if I stay in. My worst days are the days where I'm not active enough.

John Brennan, a middle-aged father, husband and professional, also believed that physical activity helped manage his Fibro symptoms. He explained that he is more physically

active now than he was at the time he first started experiencing symptoms of Fibromyalgia, and throughout our discussion he put a great deal of value on physical activity. At the end of our talk when I asked him if he had advice for other people with Fibro he reiterated,

If I had, right away, started on a daily exercise routine, I think that might have helped. I think that might have provided a more of a lasting basis for feeling good over the long term, and I think that's probably the main thing to do, is not to sort of shrivel away and just kind of sit there just because it feels good not to do exercise or not to go and do yard work or whatever is not a reason not to do it. I'd say there should be a certain degree of working through the pain, and that's something I really didn't understand [in the beginning].

Zoe also thought that exercise was an important factor in managing Fibro symptoms, and she was afraid of what would happen to her if she stopped exercising. She explained this idea by telling a story about a woman she once saw at a children's Taekwondo tournament. Other participants quickly joined in. Zoe began,

Zoe: I saw a lady, actually her child was taking Taekwondo, and she had a cane that folded out into a seat and she would go so far and then she'd put it up and sit down for a little bit, then she'd get up and walk a little more and then sit down a little bit, and that poor lady, that's the best she could do! And I thought, 'Oh my gosh.' I was thinking about myself. I'm looking at her thinking, 'Is that what I'm going to be?' So maybe that's why I say [that people with Fibro should] try to stay active thinking that if I'm active maybe... (she trails off).

Monica: and that's why my doctor told me, he said, 'The only way you're going to end up in a wheelchair is if you don't stay active'

As these examples demonstrate, many participants engaged in activities that are often categorized as leisure, but for many participants in this study, leisure time and physical activities were put to work with the specific goal of easing symptoms.

Coping through leisure. Many participants in this study also found that leisure activities could be simply enjoyable and not just utilitarian. Specifically several participants talked about using leisure as an escape from the physical, mental, and emotional pain of Fibromyalgia. For instance LeAnn Bryant talked about going for walks outside because of the calmness she feels in nature while many other participants watched TV or sought out humor in the form of comics, movies or shows. Similarly Amy, a focus group participant, explained,

I have a rule; I read the comic strips every night whether I get the rest of the newspaper read or not. You know Norman Cousins was a great example of that. When he was dealing with his cancer, he locked himself in a room and rented all kinds of funny movies and I think that's very important.

In addition to humor, participants also commonly discussed reading fiction as a means of escaping real life. For example DJ, a grandmother and interview participant explained,

Now that I'm older [and] because of the anxiety involved with Fibromyalgia [...] I try to stick with books about the coast because I miss the ocean so much. So I read about North and South Carolina and Maine, all those places that I really love. The Jersey shore. But I don't read mysteries anymore like I used to, the suspenseful things, because I'm sitting there like [She mimes being all tensed up] all scrunched up inside thinking, 'Why are you doing this to yourself?! You can read some frivolous thing with a happy ending and feel so much better!' So I try to look for the simplest things now. I'm always looking for books that are costal [and books about] families and working things out and happy endings.

Aimee, a phone interview participant and graduate student, also looked to novels to help her escape her Fibro. She said,

I've read a lot about Fibromyalgia, but now I stopped reading about it and I just go on with those books that actually get me away from it and that leave me a little bit of peacefulness.

She continued by pointing out other outlets she has that help her escape the discomfort of Fibromyalgia including writing, drawing and spending time with friends.

In addition to engaging in activities specifically to escape Fibro, many participants also talked about some leisure activities as simply being fun or enjoyable. For example John Brennan, a phone interview participant, explained that yoga was enjoyable for him even if he was in pain. He explained,

Whether or not it's actually having much of an effect on the Fibromyalgia, at least it has a calming effect which I think overall is positive. I don't feel like my body's just a source of pain, I'm sort of mindful of it and I'm not necessarily focusing on the pain, I'm just focusing on being sort of aware.

In another example, DJ, a grandmother, talked about her experience volunteering as a voting judge for the 2008 presidential election. She described that experience as a rare instance when she was able to really have a lot of fun and it inspired her to seek out more experiences like that. She explained,

I had so much fun, it was worth every minute. It really was! I would definitely do it again. I'm going to look for more experiences like that – fun - that's what I keep saying. I have this friend here that's known me since I moved here in 2001 and I keep telling her, 'You know? We don't have enough fun. We need to do more things that are fun.' So I keep hoping we're going to explore more, [go to] the basketball games or whatever, get out there and have fun.

Robin Merriwhether also talked about finding pleasure in leisure in part by making peace with the mental and emotional pain of Fibro, not just the physical pain. She spoke about coming to terms with the idea that she cannot control all aspects of her life and recognizing that she has limitations. When I asked what this outlook meant in terms of activities that she enjoys doing Robin explained,

Well this is kind of a silly thing but I've always been somebody who makes lists, and I love to garden and about a year ago I said, 'My garden is going to be a list-free zone.' And I do not make any attempt to prioritize or make lists or do things in a logical order (laughs) or any of that, I just totally do what I feel like. If I get out to the vegetable

garden and I've forgotten my seeds, fine, I walk back to the garage and I get them; but I don't do any lists, except like if I'm going to go shop for something, but that's fun. That's one area where I totally don't make any attempt (laughs) to keep track of stuff and it's just my play area, so that's a nice thing.

As these examples illustrate, leisure was not only a negative or complicating force in participants' lives; instead there were also times when leisure was a positive force providing escape, pleasure and fun.

It's all about choices. As a consequence of both their search for more balanced lives as well as the very real limitations they faced as a result of being in chronic pain, many participants not only engaged in leisure-based self care but also sought to find an overall balance in the ways they spent their time. Most participants spoke about carefully gauging how they wanted to spend their time or expend their limited energy reserves and whether or not they felt that a particular activity was worth additional pain or discomfort. Karen Blackmore, middle-aged phone interview participant who was focused on exercise and weight control as part of her Fibromyalgia management plan, felt that these daily choices and trade-offs are a necessary part of life with Fibromyalgia. She explained, "People who don't have Fibromyalgia need to understand, as my doctor explained, [that] it's not a disease that you die from but that you will die with. It's something that you just have to learn to live with." Karen's approach to living with Fibro was to engage in as many different types of exercise as possible regardless of any discomfort that may come from her participation. DJ also provided a particularly powerful example of this idea. During our interview she spoke frequently and fondly of her grandchildren and so I asked,

Megan: So does your Fibro affect your time with your grandchildren?

DJ: Oh yeah, yeah, with the lifting. I could lift them when they were babies but once they reached, really more than 10 pounds, I wasn't supposed to be doing the lifting. But I

made a conscious decision, ongoing, which things I will do knowing that I'm going to pay for it and which things aren't worth it. And my grandchildren usually win out. It's like [if my choice is to] carry [my granddaughter] to bed or not, I'll carry her to bed, even if I know the back or the neck is going to hurt the next day. It's like, 'Oh well,' just use one of those [heat] patches on my neck, you know, because it... (she trails off)

Megan: It's a choice?

DJ: It is. It's a choice. It's a choice - you gotta pay a little bit of a price but the price has never been too high so far.

Megan: Do you feel like there are a lot of choices involved with Fibro?

DJ: Everyday. Everyday. Just choosing to accept, or not, the diagnosis is an ongoing choice, everyday. I mean because you, I don't want to become Fibromyalgia. It isn't who I am and I'd never defined myself by that before, and so I refused to make it who I am now because there are days where I know that it's definitely making some decisions for me.

As DJ's example illustrates, pain did not always deter participants from engaging in the daily activities that they enjoyed. Instead, participants made choices about how much pain they were willing to put up with and in exchange for what sorts of benefits. LeAnn Bryant, a trim middle-aged married professional and focus group participant, summarized this approach to daily life with Fibro when she said,

Someone told me, I don't remember who it was, but somebody said, 'Sometimes it's just worth it, the pain's worth it, because you've got to go do things that you have to decided that you're going to do.'

Often times, as DJ's example illustrates, participants were willing to suffer a certain amount of pain in exchange for engaging in particularly treasured experiences. For instance Penny explained,

Penny: [My daughter] and I have a tradition that we go to Indianapolis before Christmas and spend the night, and both of us do that and we push ourselves because it is something we enjoy doing and it's quality time together. But once we're done, you know, we both just drop.

Megan: Right, right.

Penny: -and so it's measuring, I think, and weighing out the things that you feel you have to do. I see a psychologist who talks about, 'Do you really have to do those things?' certain things, you know. 'If you had a broken leg, would that still matter?' But you find yourself weighing out - what can I do on any given day?

John Brennan also spoke about choosing to do things he knew would trigger Fibro pain in exchange for being involved in meaningful activities. His approach to making these sorts of trade-offs emphasized attitude and mental toughness. He explained,

John Brennan: Typically I try not to let [Fibro] impact me as much as possible in terms of my mood and sometimes it's difficult, but for the most part on the average day, you know, going out to do something fun, pretty much I just block it out. I try not to pay attention to the pain and just go ahead and enjoy going out to dinner or whatever it may be.

Megan: Okay. How do you do that? Block it out?

John: I don't know. I think it's just kind of ignoring or focusing away from the pain impulses, you know because even when I don't feel like the Fibro's bad, if I sit there, you

know, if I sit in the chair or lay in bed and think about how my body feels. It doesn't feel good. Even at its best. And so I think I've trained myself, it's kind of like when you have olfactory fatigue, you know when you can smell something very strong, and then over time you can smell it less. I think that's kind of what my brain is doing a little bit is I've learned to sort of ignore the day-to-day pain to a certain degree.

However, even once participants had decided that continuing a certain activity was worth the pain and fatigue; many of them still needed or wanted to modify those activities so that they would be less taxing. Many participants used aids to help them modify their daily activities so that they could still regularly participate. These aids ranged from canes, special shoes or shoe inserts to help with walking to pillows and heating pads to help with extended periods of sitting. In one of the focus groups in particular, participants spent a long time talking about the specific types of insoles and shoes that they wore to help relieve the pressure and pain in their feet. Ann, an older focus group participant who was married and worked full-time at a library began,

Ann: I used to walk all the time, and then I quit. My feet hurt, my legs hurt, my back hurt, I could not walk a half a block! Walking from Gregory to Green Street just about killed me! And then I went to a podiatrist and he says, 'Here, order these \$150 New Balance tennis shoes and wear them all the time,' and I can walk more now. It's one of those things where sometimes [you have to] put out a little bit of extra money, effort, time.

Zoe: Well yeah I think especially if you're going to do walking or anything you need good support.

[The group begins to laugh because Patrick has pulled out the inserts that go in his shoes to illustrate Zoe's point.]

LeAnn Bryant: I got one a million years ago from a podiatrist and mine is actually like a very hard-

Voice: -hard plastic, yeah.

Zoe: Yes. I went to a podiatrist and he told me I had to go get some leather Red Cross lace-ups to wear with my dresses [the women in the group laugh] and I said, 'I can't do it!' [more laughter] so I ended up with a leather pair of New Balance. I compromised with it, but he said, 'They have to be brand new, lace them *very* tight' and I happened to be lucky - it happened to be when everyone was wearing the bobby socks over the hose with the tennis shoes to go to and from work and I just wore them all day.

Some participants' choices and tradeoffs involved modifying their leisure repertoires altogether. In particular several participants talked about beginning new daily activities to replace regular activities that had become too difficult. Doing so allowed them to maintain a certain level of activity without experiencing too much pain or fatigue. For example Robin Merriwether, a middle-aged female phone interview participant who is on disability due to Fibromyalgia, became a member of the bell choir at her church after her Fibromyalgia began. She said that she liked the bells because of their ease of use, and additionally being in the bell choir allowed her to be social and involved despite her difficulties with Fibro Fog. In particular she said that the bells suited her because she did not have to perform the kinds of memorization and fast music reading that are often required to play other instruments. She explained that, "part of the bell choir is that you have to be very in the moment, and so that's something I can still do just fine (laughs)."

This section illustrates that for participants in this study, living with Fibromyalgia on a daily basis means making choices about what and how much to do in a day and how much

discomfort to tolerate in exchange for something good. Moreover, once the decision had been made to participate in an activity, participants often needed to modify that activity in some way so that they could participate regularly. Nevertheless, making choices and modifications did allow participants to continue some of their everyday activities.

All this stuff I used to do. However, despite the choices and tradeoffs that allowed participants to continue some of their regular activities, there were still activities, obligations and functions that participants could no longer do or were very limited in doing. Rose Turner, a focus group participant, touched on this when she talked about reducing her physical activity levels despite a recent diagnosis of pre-diabetes. She explained, “I can’t do as much, I can do, but I can’t do as much.” Similarly for Sandy, Fibromyalgia meant that she too had to reduce her daily activities although it also taught her to say ‘no’ on ways that she had not done before. She explained,

Sandy: I think I’ve limited things a lot and I’ve realized that it’s okay to say ‘no’ to some of those things or not try to do everything I used to do because then it is too much, it ends up creating more pain and more fatigue. (She laughs). [So] just letting go some of that pressure on myself of [thinking] ‘I’ve got to be able to do all this stuff I used to do and why can’t I?’ It is okay sometimes to say ‘no.’

Similarly John Brennan, the husband and father of small children, said,

We used to go much more often to museums or parks or zoos and things like that that would involve a lot of walking. I like to say that part of [us not doing that anymore is] because I’m just busier now than I used to be, but I think really a lot of it has to do with just that it’s difficult, not so much with the walking [or] with the muscle pain per say but more so with just the feet. It’s not that I don’t do it at all though. There are times when

I'm feeling better and we do do those things, but I'd say overall there has been a reduction in those sorts of activities.

Grammy has also given up a lot of the regular activities that she used to do before Fibromyalgia. She explained that she has stopped doing,

Grammy: Like 99% [of my previous activities].

Megan: Like what kinds of things?

Grammy: I used to do 5K races, walking and running. I used to go take care of some horses and all that's involved with cleaning them up, [but] I haven't been around horses in I don't know how long. I just kind of, I went from being less than 50 years old in 2008 to being a 90 year old now. I just feel that way. In my head I'm not, but my body feels like that. And I think in a lot of ways I've given up [on having a life].

Niki Blackstone, a middle-aged energetic doctoral student who spoke to me over the phone, experiences a lot of fatigue and hand pain from her FMS. As a result, she has also given up a lot. In particular Niki said that she has stopped hiking and going to the gym because it is just too hard, and she has also,

Stopped doing any kind of hand craft stuff like I used to do. I don't iron. I don't cook. I don't work in the garden. I have a bunch of plants that are going to die because I can't get them in the ground.

Sometimes even newly acquired activities, even those participants thought of as "Fibro Safe," must also be given up. For example Sarah, the interview participant who had Fibromyalgia acutely for 10 years but now feels that she is cured, looked back on her years with Fibro and remembered the frustration she used to feel about not being able to do alternative activities. She explained,

Just to give you an idea, I went to a yoga class that was designed for people who had back injuries, so they were people who just came out of surgery. There was an 80 year old lady in the class, she could hold a position, they were modified positions and the teacher, who was a physical therapist, would walk around the room and make sure everybody was in the correct position before she started holding it. By the time she went around I couldn't hold the position and I would fall over. The 80 year old woman, on the other hand, (she laughs) could do everything I could and more! I went to that class a couple of times and by the end of every class I would cry [so eventually I just stopped going].

In addition to activity-based restrictions, one of the most frequently mentioned limitations facing participants in this study was the inability to sit still for long periods of time. This difficulty affected participants' leisure lives in a multitude of ways, specifically many of them had trouble sitting through movies at the theater as well as airplane flights or car trips. As a result, many participants have given up those sorts of activities in favor of watching movies at home, restricting travel, and avoiding long car rides. Those who did still choose to fly spoke about the considerable difficulties they faced in doing so, many of which were related to the safety and cost saving measures that airlines have implemented over the past few years. For example Johanna Donne had the following exchange with other participants in her focus group,

Johanna Donne: [My husband and I like to] to travel overseas, and so there are the airplane rides and the sleeping in other places where there frequently aren't microwaves to heat up [hot packs], so travel can be difficult. That doesn't mean that I don't do it, [it] just means that it's [hard]. I had a physical therapist tell me that I should stand up a lot on the airplane and-

Voice: -no-

Voice: There's no room anymore!

Johanna: Oh it's not even standing up straight; it's that the aisles are about this wide-

Voice: -right-

Voice: -and they don't want people, just for security reasons-

Johanna: -Oh yeah I know, they're always coming and telling us, 'You need to sit down.'

(Someone laughs)

These limitations also went beyond participants' everyday lives. Although a distinct discussion of gender is beyond the scope of this study, it is important to quickly note that many of the women in the study in particular talked about being limited in the number of daily chores they could complete in a day. For instance the following exchange during one of the focus groups provides a representational example of these kinds of limitations. An unidentified female participant begins,

Unidentified: I can't do anything in the yard, I can't rake a leaf, I can't-

Monica: I can't do anything for a long time or do anything over my head for a long time or I'm locked up.

Janet: Strangely enough, I'm a sweeper.

Monica: Yeah? That hurts me.

Zoe: Oh! To stand at the sink and bend over, like doing dishes! I have a dishwasher but there are things I still do by hand. Or peeling something, there's something about the posture of it.

[Group agrees]

Ann: Yeah, just standing at the table, standing at the counter, or whatever [is difficult].

As this section suggests, Fibromyalgia took its toll on the activity repertoires of most participants in this study. Although the first section of this chapter suggested that choices and tradeoffs did make some activities possible, those strategies alone were not enough to preserve the full scope of participants' everyday lives. As a result, many activities were given up permanently or only engaged in very rarely.

Conclusions. As this section demonstrates, the participants in this study had complicated relationships with their diagnoses, their health, and even their leisure time. They struggled to receive a diagnosis that was, for many, inactionable and stigmatizing. Moreover, although participants sometimes spoke about their daily lives in terms of pleasure and fun, more often they spoke about struggling and feeling limited by the types of activities they could do due to the nature of their illness. They also often mentioned feeling a sense of loss in relation to their previous pre-Fibromyalgia lives, or in comparison with the lives of others. For example when I asked John Brennan what he felt was the most important thing we had discussed in our interview he replied,

I'd say probably just how Fibromyalgia affects your daily life. Not so much in terms of routine, but things like just doing the sorts of activities that you would want to be doing. I think to me that's really been the biggest impact, you know? I can live with the pain, it bothers me, but it's something I can live with, it's more the things that I don't do that really bother me the most.

Although this feeling of loss was shared by many participants, including phone interview participant Aimee, many people I spoke to also had hope and demonstrated a determination to define themselves and their own limitations instead of letting Fibro, friends or relatives do it for

them. Aimee explained, “We’re not victims here; we’re people who are trying to live a life without giving up too much on our dreams. That’s who we are.”

Stories

The following section is made up of 5 synthesis stories drawn from aspects of many participants’ narratives. These stories are not intended to represent the experiences of any one participant; however, they are true to the overall feel of the stories that I heard throughout data collection and in particular they speak to the intricacies of participants’ experiences as they relate to my research questions. As a result, these stories reflect both the shared elements of many participants’ narratives while also allowing for focused explorations of particular aspects of those shared narratives. I created the names used in these stories and no one participant is represented by any of the characters presented below.

The first story I present takes the form of a conversation between two fictional Fibromyalgia patients: Dina Kelly and Nicole Andrews. While both women share similar social struggles with the medical profession and similar debilitating symptoms, their beliefs about the root causes of their illness are different. Dina, like many participants in the study, believes that she has had Fibromyalgia since childhood. Amy, like several other participants in the study, believes that her Fibromyalgia was caused by a life trauma. These differences result in distinct ways of thinking about both self and illness.

The second story I present focuses on the life story of Amelia Carter, a fictional woman diagnosed with Fibromyalgia during graduate school who continues to suffer from symptoms as a middle-aged woman in the workplace. Amelia’s story highlights the considerable social, familial and workplace stigma experienced by many participants in this study as a result of their inability to receive a meaningful diagnosis.

The third story I present takes the form of a letter written by Dena Jacobs, a fictional grandmother who has struggled with Fibromyalgia all her life, to her daughter Julia who was recently diagnosed with Fibromyalgia. Like many of the older participants in this study, Dena wants to provide perspective and advice to a younger generation of Fibromyalgia patients. She talks about finding balance her life, treating her symptoms, and seeking out ways to remain involved in her children's and grandchildren's lives despite her constant pain and fatigue.

The fourth story takes the form of a series of diary entries in which Dutch Sanderson, a middle-aged woman who is struggling with increasingly frequent Fibro flare-ups, tracks her activities, food and symptoms in an effort to find relationships among the three. Dutch's entries are reminiscent of parts of almost every participant's narrative as many people in this study could describe their symptoms with an almost medical accuracy, and most had a series of lifestyle protocols that they believed would protect them from the worst flare-ups.

The final story I present takes the form of an email conversation between two cousins, James Desjardin and Ruth Krantz. James was recently diagnosed with Fibromyalgia but Ruth recovered from it approximately five years ago. In their emails the two discuss coping with FMS symptoms, and Ruth shares her advice about curing Fibromyalgia. James' story specifically mirrors the experiences of the two men in this study, and Ruth's story mirrors the experiences of the one participant in the study who believed that she was able to cure herself. However, while this story centers on some of the more uncommon Fibromyalgia experiences (i.e. male or cured), it also demonstrates that most participants' experiences still share many key elements.

A Difficult Diagnosis

Dina Kelly and Nicole Andrews first met several years ago through a mutual friend and later joined the same local book club. Dina is a 68 year old married woman who is retired and

has two grown children and three grandchildren. Nicole is a 51 year old married woman who, due to her FMS, is now only employed part-time. She has three high school-aged boys. The following conversation takes place between the two women while they chat at a coffee shop following their weekly book club meeting. The two have just discovered that they share a Fibromyalgia diagnosis, but that their experiences in receiving that diagnosis were quite different.

Dina: If I think back it becomes clear that I've had Fibro probably since I was 9 or 10 years old. I also suspect, knowing what I know now, that my mother had Fibro. I remember her talking about the same kind of pain that I feel now. I think it's just in the genes but we haven't figured out where, you know? So a lot of my memories from childhood involve having pain or fatigue. I always remember aching in my joints and sometimes even stabbing pain in my legs, but the doctors always told my mother that it was from growing. He treated me with cold wet packs! Could you imagine treating Fibro that way?! But even then it wasn't just the pain, it was fatigue too. I remember when I was in school I wanted to try out for the basketball team but I just couldn't keep up with the other girls. At the time I thought that I just wasn't good enough, but now I realize that it was because of the Fibromyalgia. And of course I also had a hard time concentrating in class, and I struggled because of that even though I was a smart kid. I had a hard time concentrating and I fell a bit behind. My limitations also made it harder to make friends, the other kids had to be patient with me and things, but I got by.

I do remember one time when I was probably 12 or 13, I tried to get up in the middle of the night to go to the bathroom and the pain and weakness was so bad that I collapsed. My mother was terrified and she rushed me to the doctor but he couldn't make heads or tails of it.

Eventually, because of the time when this happened, I was tested for polio! Of course, it wasn't polio, thank God, but it took a long time to find out that it was Fibro.

Nicole: You know it's interesting that you've always had it because I hear that most people are that way, and actually that's why I originally thought that maybe my diagnosis wasn't right, you know? Maybe I had something more serious? I mean, I grew up healthy and very active, never a health problem, I barely even got colds! When I was younger I was always very busy, I worked full time, we adopted three boys, and I was whizzing around to soccer practice and this errand and that place, but then when I was in my 40's I think all of that caught up to me. One year, all in the same year, one of our sons was nearly kidnapped and my sister passed away and then my husband was laid off from his job. I was working full-time at the time and trying to keep our family together and I started feeling acutely fatigued. Of course, I thought nothing of it at first given what I was going through, but then the fatigue turned into pain and I got scared. I went to the doctor but he said I was just overtired and he told me I should get more rest, maybe take some over-the-counter pain relievers. I tried that but eventually the pain and stiffness got so bad that I could barely get out of bed. I remember being in so much pain that wearing clothes hurt. I felt like the princess and the pea! And you know, I think it's because my body gave up; it couldn't keep up with what was happening to me emotionally. I'd just been through too much for me to handle and I was exhausted and that caused it, I think that triggered it. You know they still don't know why we have this thing, and I just think that's gotta be a part of it.

Dina: So what did you do, I mean, how did you find out it was Fibro?

Nicole: Well I went to the doctor, but you know how that is. I must have seen three or four people and no one knew what was going on. After about the second doctor's visit I got the feeling that they thought that I was making it all up! They tested me for MS and lupus and all of

those things and nothing was positive, but I still had pain and fatigue. Sometimes I would feel almost like I'd taken too much cold medicine, you know? I'd be wobbly and dizzy and I just had a hard time concentrating. I would tell my doctor that I was so uncomfortable that I was missing work and I think he just assumed that I didn't want to work full-time anymore. It was to the point where all I could do was either sit in a hot bathtub or lie on the couch with heating pads everywhere. It was awful! So I kept trying new doctors and new doctors. I probably saw six or seven total. One of them even told me I had "Internet disease" – he said that I'd read about Fibro on the internet and convinced myself I had it! I was so angry. But finally I heard about a doctor from a friend of mine and this doctor was able to diagnose me using the trigger points test and I think because my pain was mostly at the places where the muscle attaches, you know? I think almost every one of the points he touched – I just cried out in pain! He told me that I had a certain case of Fibromyalgia, and by that time over two years had gone by! You know some days I don't know what good it is to have a diagnosis anyway, nothing really seemed to change except that I knew I wasn't dying from something serious, you know?

Dina: Well I can sympathize with that. Back when I first started going to the doctor they sent me to a rheumatologist first – I think they just didn't know what to think of me! I mean, imagine a little 12 year old girl at the rheumatologists' office! He must have thought it was strange. In fact, he said that because of my age and being near puberty that my symptoms were from depression, so he didn't even examine me! He just sent me straight to a psychologist because he thought I needed medications. I remember feeling horribly misunderstood, I cried for days after I got that referral because I thought no one believed me! But I went to the psychologist anyway and you know what? That was the beginning of some real help. The fatigue didn't improve, but the psychologist did give me some mental relaxation and pain

management techniques that helped. And in that way he did buy me some time until they started to learn more about Fibro. Eventually, I'd say when I was in my late 40's, I was finally diagnosed with Fibro; only at that time they were calling it "Fibromyositis" and they didn't have trigger point tests or anything. I just remember my doctor saying that he'd read an article about it and recognized what was going on. But that moment of diagnosis was a really big step! I remember thinking, "Oh THAT'S what it is, so that's what I've been dealing with!" I felt almost relieved – I wasn't going to die I just had to learn how to live with it, you know? But dealing with other people was still difficult; a lot of my friends didn't seem to know what to make of my diagnosis when I told them about it. I remember a few months later one of my friends at church said, "Well, now that they finally know what's wrong with you, you can just take Lyrica and you'll be cured, right?" I just wanted to say, "It's not that easy!!" She didn't seem to understand, and that part is hard. But at least now I'm going to a physician, although I still see my psychologist, and I'm on some mild antidepressants for sleeping.

Nicole: Me too. Are they helping?

Dina: I still toss and turn some, but not as badly, so I guess that's improvement? I have Irritable Bowel now too so I really work hard to take care of myself and keep my stress levels down. I've been trying this art therapy class – we do skits and sometimes they bring in a pottery wheel or some canvas and we create. It just feels good to be able to create in the face of pain, you know? I'm also leading a support group here locally; it's nice to be around people who understand what I'm going through. And we don't just talk about how bad things are, we talk a lot about what helps and whose doctor is prescribing what and sometimes we just get together and go for coffee. I like having a social life with people who understand that some days I don't

feel well enough to be there or other days I may not say much because I'm in too much pain, but I'm still enjoying their company.

Nicole: Absolutely. Keeping up with my pre-Fibro friends is one of the hardest parts. I'm always the one leaving early or backing out of plans after I say yes and that's tough to explain. I get tired of saying that I'm in too much pain or I'm too tired. But I just keep hoping that now that my life is slower, with fewer emotional rollercoasters, maybe my body will respond and go back to the way it was before. I just can't help but think that I brought this on myself somehow, that my life was just too stressful before. When I look back at all the things I used to do, and I didn't sleep, I was just so energetic, I think maybe I used up a lot of my reserves and my body just couldn't recover. So I've been trying to get back to a balanced life. I do some meditation and play with my dog and I just try to relax. I've started reading these great comedy novels and they're fun because I don't have to concentrate too much to follow the story and they make me laugh – which is great!

Dina: You know, for better or worse Fibro teaches you to find balance and make choices about how you spend your energy.

Nicole: Ha! I guess that's true...

What does it mean? Dina and Nicole's exchange is representative of participants' two dominant ways of thinking about Fibromyalgia Syndrome. Several participants in the study, like Dina, felt that they had been born with Fibromyalgia. These participants used their narratives to draw coherent lines from their childhood experiences to their current diagnosis of Fibromyalgia. Many of them talked about always having been different, always having experienced pain, and never having known why until adulthood when they were diagnosed with Fibromyalgia Syndrome. This pattern of highlighting coherence from childhood to adulthood could be likened

to the narratives told by gays and lesbians in the coming out stories studied by Penelope and Wolf (1989). For these participants, FMS was an integral part of their identity and was used to explain the missed opportunities and disparities between their experiences and the experiences of their healthy peers.

However another group of participants, like Nicole, believed that they had contracted FMS as a result of physical or emotional stressors during their adult lives. These participants did not exhibit as much narrative familiarity with FMS and they did not believe that FMS had always been a part of their lives. For many of them, FMS had negatively changed a life that was previously energetic, productive, and care-free. In that way, FMS represented the second phase of their lives, a phase that was characterized by struggle, hardship, and loss. These differences in belief about the origins of FMS (genetic versus contracted) were evident in the meta-narratives of the participants and may have influenced participants' interactions with the sick role.

What If You Don't Look Sick?

In this second story Amelia Carter first experiences FMS while pursuing her MBA although the illness continues to affect her as a professional woman. Her story is meant to highlight the considerable social, family-related and workplace-related stress experienced by many participants as a result of their diagnosis.

Amelia has always struggled with anxiety and sometimes suffers from bouts of what she's been told are panic attacks. Now in her mid-thirties Amelia often seems soft-spoken and a bit melancholy, but nevertheless she is the sort of person who seeks out deep relationships and makes friends for life. Although Amelia's parents and her one sibling live in another state, she has worked hard to remain close to her family and calls home at least once a week. In this way,

Amelia is much like many other young people with careers, she wants to make her parents proud and she wants to be accepted and successful in the workplace.

Amelia recently completed her MBA at a local university, and it was during her graduate work that she began experiencing periods of intense fatigue and pain in addition to her pre-existing anxiety and panic attacks. She went to the doctor but was told that her newfound symptoms were simply manifestations of existing conditions, possibly made more severe by the intensity of her graduate work. Nevertheless her symptoms continued to worsen, and after experiencing a particularly bad case of the flu, Amelia's condition took a turn for the worse. She could make it through most of the day but then she would have to spend the rest of the evening lying in a hot bath trying to lessen her aches and pains. Eventually the fatigue and pain caught up to Amelia, she became depressed and stopped eating. She rapidly lost weight, and no longer responded to her friend's invitations or her family's phone calls. She began making excuses for not spending time with people because she got tired of saying, "I don't feel well" and hearing an exasperated sigh on the other end of the phone. Her world started to shrink and her social contacts lessened. Amelia went to doctor after doctor but got nothing except a prescription for antidepressants. The pain continued and some days her flare-ups were so bad that she couldn't get out of bed. Instead she would lay in her room, surrounded by heat packs, and took as many over-the-counter pain medications as she could without overdosing. Some of Amelia's friends were sympathetic and believed that something was horribly wrong, but many friends felt that she was exaggerating and told her that she was being overly dramatic. After all, she didn't *look* sick. Amelia was hurt and watched as her large group of friends dwindled. Her parents became concerned and finally, after visiting and seeing her poor physical condition, they took her back to a specialist to figure out what was wrong. Amelia was subjected to a battery of tests for

everything from multiple sclerosis to lupus to cancer to AIDS, and all of the results were, for better or worse, negative. Amelia's pain and fatigue continued, and her flare-ups became more frequent. Finally Amelia's parents took her to a rheumatologist and she was diagnosed with Fibromyalgia. She went online to read more about it and it all made sense – this is what she'd been dealing with for so long! People had thought she was lazy but she wasn't! She was happy to have her diagnosis and relieved to find out that she wasn't dying of a more serious condition. But Amelia also realized there was no cure and so she needed to make significant lifestyle changes to live with her condition. Those changes, unfortunately, interfered with her ability to study, work or spend time with friends. She cut out evening activities to conserve her energy, she got up earlier to take advantage of the time of day she felt her best, and she gave up alcohol so she could avoid any further stressors to her system. As a result, she found herself abandoned by even more friends who became frustrated with her erratic ability to spend time with them, and she was lectured by people who felt that her new restrictions were self-indulgent and unnecessary.

Nevertheless, another year passed, and with some modifications to her schedule, Amelia was able to finish her MBA. Despite her continued periods of fatigue and pain, Amelia went on to seek full-time employment. She was hired at a large insurance firm as a mid-level manager and had high hopes for her future. But repeated sick days and periods of low productivity meant that she never progressed past her initial level of responsibility. The vibrant woman who once loved to go dancing with friends and spend time with family now struggled to make it through a day at work. She became resentful of her co-workers' continual comments about her absenteeism and their insinuations that she was lazy, or worse, a liar. Just like her friends in

graduate school, Amelia's colleagues at work couldn't *see* that anything was wrong. She simply didn't look sick!

Despite a lack of social support at work, Amelia continued to visit doctors in search of remedies but after thousands of dollars in insurance co-pays and hours of missed work to attend appointments, she was no better off than when she began. By the time I spoke to Amelia she'd created a façade to protect herself in social situations with friends or at work. She took on qualities that were unlike her previous self, speaking brusquely to colleagues and avoiding conversation. She may not have looked sick, but she acted in such a way as to make people want to avoid her as if she were sick. While she continues to visit doctors in the hopes of a cure, Amelia has in large part resigned herself to her illness and the terrible effects it has on her social life and mental health.

What does it mean? Amelia's story is representative of the acute social stigma experienced by nearly every participant in this study. Like many of the people I spoke with, Amelia has a hard time convincing her family and friends that her diagnosis is real. As a result, her social world has constricted and she struggles to maintain friendships. Moreover, Amelia, like many participants in this study, still works full-time. As a result, she experiences the added burden of convincing her coworkers that her time away from the office is due to a real illness and is not due to laziness or a lack of professionalism. As a result of her struggle with the sick role, particularly social acceptance for her illness, Amelia experiences a great deal of psychological and emotional stress. This stress was also evident in the narratives of almost every participant in this study and serves to reinforce the negative consequences of a failure to fulfill the sick role.

It's All About Choices

The following is a letter written by Dena Jacobs to her daughter Julia Jacobs. Dena, now a retired grandmother, has had Fibromyalgia for over 30 years whereas Julia, a corporate manager and mother of two, was just recently diagnosed. Like many of the older participants in this study, Dena wants to help her daughter find balance and perspective in the face of Fibromyalgia. She also has her own theories about why so many more women are affected than men.

Ms. Julia Jacobs

114 Federal Way

Austin, Texas 78704

Dear Julia,

I was both sad and relieved this morning when I got your call this morning from the doctor's office. I never wanted you to have Fibro like me, but I'm also glad that it's not something more serious. I guess it's comforting that your Fibro didn't follow a cancer diagnosis the way mine did, but still I wish I had given you better genes. Regardless I believe that there are ways to live with this thing, honey, you just have to be willing to make choices and let some things go. You know after years with this disease and after talking to other women who have it, sometimes I wonder if women get Fibro as a way of telling us to slow down. I know you've always wanted to do it all – mother, wife, professional – it's just so much to handle. I look at young women like you and you're all doing the same things we did – you're giving too much, you're trying to do everything, and I just feel so sad. I think only now, at my age, am I learning

to really be true to myself. So I suppose in that way it's not all hopeless. I just want you to be able to get a handle on this thing before you're as old as me! It's like my doctor said, this isn't a disease you die from, it's a disease you live with. And you can live with it!

My first bit of advice, unsolicited as it is, is that you have to learn to let certain things go. When I look back I realize how much guilt factored into decisions I've made over the years, and I wonder - if I'd learned to accept Fibro sooner, could I have relaxed and tried to enjoy life more? So I hope that you learn quickly that if the laundry doesn't get done or you take a nap over your lunch hour, that's okay. The important thing is that you're able to enjoy the time you have with your family and live as fulfilling a life as possible. I believe that I've made it this long with Fibro without any serious depression because I've learned to make choices. And that doesn't always mean choosing to avoid the pain. Sometimes playing tag with my grandson or helping you cook Thanksgiving dinner is worth a little extra pain and fatigue. Other days I know that shortening my "to do" list or taking an extra nap is worth a little disappointment in myself for not doing what I set out to do. I've learned that while I may have to live with Fibro, I don't have to be Fibro.

You also have to take time for yourself. Keep going to your painting classes and take naps when you're tired. Find activities that will help you relax or energize. Find those moments of fun in your life – you still deserve to be happy! Also, don't be afraid to ask for help or to shop for just the right doctor. At times in my life I've found that antidepressants or sleeping pills help me sleep more soundly. Don't be afraid to go to your doctor and ask for medication, and if you don't like that doctor, go to a different one. I know that some physicians, and some of your friends, may make you feel like you should be able to control this all on your own, but I know that you can't. You just have to be patient and do what you can to make yourself feel better.

Don't expect too much of yourself, and don't be surprised when other people are hard on you. They simply can't know what it's like to be in pain all the time. Remember honey, you don't look sick, you look normal. People have a hard time with that, and they may get frustrated with you, but you just have to do what you can and know that it's good enough.

Anyway, most of all I want you to know that I love you and support you and I'm here if you need advice or help. We'll get through this and you'll see that life can still be fun and worthwhile. Give my love to Dan and the kids. I hope I can get down there to see you soon!

Love, Mom

What does it mean? Dena's letter to her daughter is meant to represent several meta-themes that emerged throughout the course of this study. The most substantial of those meta-themes is the idea that self-care is important, and that caring for the self may involve both choosing to experience, as well as choosing to avoid, pain and fatigue. Many of the older participants in this study, particularly those who had experienced FMS for quite some time, were eager to use this research experience as an outlet for providing wisdom to younger patients. The primary lesson in their stories was that the successful navigation of FMS requires striving for a balanced life and preserving time for oneself. Dena's letter reflects this lesson.

However, Dena's letter also reflects a few subtler themes, namely the pervasive belief among participants in this study that Fibromyalgia is genetic and may be passed, primarily, from mother to daughter. Dena's letter also hints at some underlying beliefs about the links between gender and Fibromyalgia, primarily the potential link between women's overextension via the ethic of care and their higher prevalence of FMS. Only one participant explicitly suggested that women are overextended and are therefore more likely to develop Fibromyalgia than men, but

many others seemed to implicitly suggest the same hypothesis. It is certainly an interesting idea and one worthy of further discussion.

Searching for Triggers

In this section Dutch Sanderson, a middle-aged woman struggling Fibro flare-ups, logs her activities, food and symptoms in an effort to find relationships among the three. Dutch's entries are reminiscent of parts of almost every participant's narrative as many people in this study could describe their symptoms with an almost medical accuracy, and most had a series of lifestyle protocols that they believed would protect them from the worst flare-ups.

August 8th, 2009

My symptoms began approximately 2 years ago, almost immediately following a car accident. I can't help but think that the two are related, but my doctors didn't seem to think so. One doctor said, "Well, you know, women of a certain age...." But I knew this wasn't just menopause so I insisted that they get to the bottom of it. They ran a series of tests, including X-rays and MRIs and eventually they just seemed to settle on Fibromyalgia. I never had any formal tests for the disease; I guess they just ruled everything else out. It's been particularly difficult because I don't have any external symptoms, so people aren't really sure how to react. My flare-ups have whittled away all my sick days and I'm worried that my job is in danger. It's time to take control of this myself! I'm starting this log to see if I can find links among my symptoms and the things I eat or do each day. Maybe if I can find a pattern I can keep the worst parts of this disease at bay.

This past weekend my pain and fatigue have been bad but I don't think I'm in a total flare-up. All my joints are really stiff in the morning, and my right elbow has been particularly

painful. It's almost like I have bursitis in my elbow and then just generalized joint pain everywhere else. My neck is also very stiff, more so on the right side. I haven't been able to ride my bike lately, or even brush my hair some mornings, but I can still get through the workday okay. I've been taking Amatriptiline for the past two months after switching from Effexor and I think it's helped a little bit, but I'm still just so tired. Relaxing and stretching have seemed to help a little so maybe I'll try yoga this week and see if that makes a difference? Wish me luck!

Pain 6/10

Helping: stretching, Amatriptiline

Hurting: Mornings, fatigue in afternoon, right elbow motion

August 10th, 2009

The past two days my pain escalated to almost unbearable. I spent most of the yesterday and today in bed. I ache all over; it even hurts to have bed sheets touching me. And what's even worse is that my mind feels all foggy, it's hard to remember words and exhausting to try and write.

It's to the point that I've had trouble taking care of myself. I tried to get up yesterday to do laundry but by the time I got to the bottom of the stairs I had to stop and rest for over an hour before I could do anything. It was really scary, and since Jim doesn't get home from work until 6 these days, I was afraid I'd be stuck down there all afternoon. Finally I was able to get back upstairs, but by the time I made it I was so exhausted and sore that I could barely move.

After the flare-up started I added Ibuprofen to my medication regimen, but I haven't noticed much of a difference. I still want to try yoga but I'm much too exhausted. I haven't been on my bike in days so I know that once I do get back on – it's going to hurt! I'm also afraid

that if I go to an exercise class, even just yoga, and the instructor doesn't understand Fibro, she may suggest things that will hurt even worse than what I have now. Maybe I'll see if I can find a yoga DVD online instead.

I did spend some time at the computer today and in some of the chat rooms they're saying that giving up dairy and gluten helps, so I figure what the hell. As soon as I can get around again, I'm going to shop for some different food. I'm really hoping that by tomorrow this flare-up will start to fade, I'm not sure how much more work I can miss without getting in trouble. I don't have any sick days left as it is.

Pain 9/10

Helping: Nothing

Hurting: Everything

Foods: no dairy, no gluten

August 12th, 2009

I think the dairy and gluten diet is working! My pain is reduced, I seem to have a bit more energy, and my flare-up has passed. I got a yoga DVD at the store and I've tried it once. I got back on my bike today too and it felt wonderful even though I'm exhausted from my ride. I'm trying to pace myself by doing just a few exercises a day. I'm still taking Amatriptiline and Dr. Redfield prescribed a half dose of antidepressants to help me sleep, so I think both of those are helping too. I'm trying to pace myself today, I remember from times past that if I try and get too much done when I feel good, it can send me into another flare-up. It's so hard not to want to do all the things I've been putting off! Maybe I can even meet Jill and Katie for dinner tonight!

Pain: 3/10

Helping: Tylenol, antidepressants, yoga, new diet

Hurting: mild joint discomfort early in the morning and late at night

Foods: no dairy, no gluten

August 15th, 2009

I'm not so sure that my diet change is helping after all. This is so frustrating – it seems like no matter what I do the pain gets worse or it gets better – it's like it has a mind of its own! Lately my pain is back up a bit but not too bad. I haven't done as much yoga as I'd like but I'm still trying to do a few stretches in the morning. I talked to Dr. Redfield about Lyrica but he said that with my sulfa allergies it's probably not safe. I've even heard that some people are having horrible reactions to it, personality changes and things like that. Scary! So it's probably best that I not try it anyway. I did read online about a cough syrup ingredient, something called Guaifenesin, that's helped a few people, I think I'll ask Bonnie about that next time I see her. Maybe she's had luck with it and just forgot to tell me? Ha-ha. My plan for the next week is to keep up with my new diet (it can't hurt, right?) and try and to exercise at least 3 times a week no matter how I feel. I'm also thinking about finding a support group here in town. I don't want to just sit around and complain with other people, but if there are people who are finding things that work, I want to know about them. I can't keep living my whole life like this, there has to be some kind of cure.

Pain: 5/10

Helping: Tylenol, antidepressants, diet?

Hurting: mornings, late evenings, stairs (my knees have been bad today)

Foods: No dairy, no gluten, also tried to take extra vitamins

What does it mean? Many participants, like Dutch, are not able to receive definitive or actionable information from their doctors about the causes or potential treatments of Fibromyalgia. As a result, many participants in this study became their own medical researchers and epidemiologists by searching for linkages among their leisure-based self-care behaviors, nutritional choices, medications, and symptoms. This medical detective work represents an empowered reaction to the failure to fulfill the sick role, but also highlights the aspects of participants' illness experiences that remain lacking (i.e. an actionable diagnosis and a reliable course of treatment).

Advice for a Cure

The following is an email conversation between Ruth Krantz and her cousin, James Desjardin. Ruth believes that she has cured her Fibromyalgia while James has just recently been diagnosed. The following exchange mirrors the experiences of the one participant in this study who felt that she cured her Fibro, and also highlights the experiences of the two men in this study. I grouped these two kinds of stories together as a way of creating one alternative story – a story about being cured and a story about being a man with Fibromyalgia.

From: Ruth Krantz <ruthee@gmail.com>

To: James Desjardin <jdesjardin@gmail.com>

Date: Monday, February 8, 2009 at 6:42pm

Subject: Fibro Diagnosis?

Hi James,

My mom just called me and told me that you were diagnosed with Fibro last week?! I'm so sorry to hear that. I remember when I got my diagnosis I was both relieved that it wasn't something more serious but also discouraged that it wasn't something easier to treat. Knowing you you've read a lot online about Fibro already, and I'm not sure who your doctor is or what her approach might be, but if you want, we should get together and talk about it sometime. I know it may sound crazy because Fibro is supposed to be chronic, but I really think I'm cured and if anything I learned can help you, I'm more than willing to share it. Let me know, and say "hi" to Jackie and the girls.

Take care, Ruth

From: James Desjardin <jdesjardin@gmail.com>

To: Ruth Krantz <ruthee@gmail.com>

Date: Tuesday, February 9, 2009 at 7:23pm

Subject: Re: Fibro Diagnosis?

Ruth,

Thanks for the email. It's nice to hear from someone who's been through it. All this time I thought I had MS or maybe even cancer, so my diagnosis is taking some getting used to. I'm relieved but I'm also confused about where to go from here. My doctor said that men don't usually get Fibromyalgia but I guess since my sister Cassie has Chronic Fatigue maybe it is genetic?

I guess in terms of pain management, most days I just try and ignore the pain, I just don't think about it. I'm trying to sort of train myself, kind of like when you have olfactory fatigue,

you know, you just don't smell things if you've been in the room long enough. I'm hoping I can do the same thing with pain. Most days I try and go out and do the things I want to do. I don't want Christine or the kids to have to miss out on things because of me. I've tried over-the-counter pain medications and I guess they take the edge off but the hard part is really that I'm so tired all the time. I've had trouble concentrating at work, reading articles and concentrating is a lot harder than it used to be. I read somewhere that it's called "Fibro Fog?" I can't hike like I used to and the snowstorms we've been getting have really made my joints ache. But all in all I guess I'm doing okay. I can sometimes use those muscle creams or just go to bed earlier and that seems to help.

I am curious though, what did you do to get better? I certainly don't intend to have this thing my whole life. The goal I've set for myself is to be rid of it by Christmas next year but I need a plan. Anything you can tell me would be great.

Take care, James

From: Ruth Krantz <ruthee@gmail.com>

To: James Desjardin <jdesjardin@gmail.com>

Date: Wednesday, February 10, 2009 at 10:13pm

Subject: Re: Re: Fibro Diagnosis?

Hiya James,

It sounds like you're thinking positively about this, which is definitely good. Who is your doctor again? I think the doctor you choose really makes a big difference. I saw quite a few people before I found someone who believed that Fibro existed and also believed it could be

cured. I'm not saying you should go to one of those special Fibro retreats or anything, my doctor was at a teaching hospital in Boston where I lived at the time, but you should go to someone who believes you and who believes you can be cured, you know? I also think it's really important to systematically track the things that help you get better and the things that make you worse. I tried to keep a log so I could determine patterns.

I'd also say that you want to stay in shape and even try to build muscle. The more tired and sore you are, the less active you are, and then the less you can do. It's a viscous cycle and you have to break it from day one. I think even just gradually building up the amount of time you walk each day, and really focusing on mindful use of your body will help. I took up cycling, I found I could use a recumbent bike and avoid a lot of the back problems I'd get with a regular set up. I took advantage of my periods of energy in the morning to get in some exercise, so that kind of scheduling really helped.

Dietary changes also worked for me. Starting right now you have to get on 6,000 milligrams of vitamin C, take anything with a malic acid, and definitely get on a B-12 stress complex. You hear about this a lot online, but I also cut out dairy, artificial sweeteners (they turn into formaldehyde in your body!) and of course alcohol. I also made sure to eat a lot of fresh vegetables and lean meats. I think you have to keep your body really running on pure fuels.

I also went to a lot of classes and I built this repertoire of things that I did every day. I took yoga, even though it hurt so bad sometimes I would just go home and cry, but I wanted to stay flexible and build muscle so I just stayed with it. I did meditation with a healer that I found in my hometown who was just amazing, but I think you could also do the same at like a community class or maybe even ordering tapes online? I also practiced the Alexander Technique

– it really helped me re-learn how to move and how to use my body. I think over time with all my work and things my body just became out of whack and didn't work right anymore, you know? I think that was part of what caused it; I'd allowed my life to become unbalanced. Eventually I went from barely being able to walk into work to hiking and rock climbing again, but it took a while. All in all I'd say it took me around 4 years to really recover, but I did and I've heard of other people who recovered too.

Anyway, let me know if you want me to send you more specifics. I think I still have some of my logs and paperwork from that time and I'd be happy to pass them along.

Love, Ruth

From: James Desjardin <jdesjardin@gmail.com>

To: Ruth Krantz <ruthee@gmail.com>

Date: Thursday, February 11, 2009 at 11:21am

Subject: Re: Re: Re: Fibro Diagnosis?

Hi Ruth,

Thank you for getting back to me so quickly and for the great tips. I've been looking around more online and I found the names of some doctors here locally who specifically say that they treat Fibro. One of them is an osteopathic doctor? I hadn't heard of that before but I guess they say they're better with pain? I'm going to make an appointment and see what I think.

Jackie says that I should maybe go to part-time at work for a while, I know I'd heard you essentially took a year off to work on getting better, but I'm not sure I'm ready to do that yet. I just think a lot of this is mental, you know? So I'm trying to work on creating mental blocks so

it doesn't bother me so much. I also saw at the local library that there's a support group that meets here each month, I'm not sure I'm ready for that but I'm going to think about it. Maybe they'd have some advice on what to do, although I know you think that the way to get cured is not to get comfortable with your illness. I guess I get that too.

Anyway, I'll keep you posted on how things are going. I haven't had a really bad flare-up in a few weeks, so that seems like progress, but this disease is so unpredictable that I never really feel like I can relax or hope for the best. Maybe we can talk more about it this weekend?

Thanks again and take care, James

What does it mean? Ruth and James represent the outlier experiences captured during this study. In particular, Ruth represents the one woman in this study who believed that she had been cured of FMS whereas James represents the experiences of the two men in the study. The email exchange between Ruth and James was designed to highlight notable variances that came to light during my interactions with these three individuals. For instance, Ruth placed a great deal of importance on leisure-based self-care, much more so than anyone else I spoke with and so much so that she believed that her self-designed leisure-and-nutrition-based self-care program had cured her Fibromyalgia. Although her experiences also fit with many of the other themes presented previously, her tenacious adherence to a self-care *curative* regimen, and her willingness to try doctor after doctor until she found one who would help her put her plan into action, was distinctive.

James represents the reactions of the two men in this study to their Fibromyalgia symptoms, and in particular draws attention to the tendency of the men in this study to avoid thinking about or dealing with their pain. Instead both men, who spoke to me independently and never met each other, placed a great deal of emphasis on working through the pain and

continuing to do the things they loved to do so that their families would not be impacted by their illness. While neither man was able to continue completely in their former activities, both nevertheless stressed the importance of trying to do so while making their best efforts to ignore their discomfort. Although both men also shared in many of the themes presented earlier, their approaches to pain, particularly pain management and activity allocation, was notable.

Moreover, while I am not able to say that the experiences represented by James or Ruth are representative of all other FMS patients in similar situations, it was nevertheless important to provide a forum for addressing the elements of their narratives which were distinct from the main set of themes provided by the other participants.

Chapter 5 – Interpretations of Findings

The current study approached sick role theory as a dominant yet implicit societal narrative outlining the expected behavior of anyone with an illness. Although critics of sick role theory have suggested that it should not be applied to people with Fibromyalgia or other chronic conditions, I designed the current study under the premise that society has the same expectations for the behavior of the ill, regardless of the nature or type of illness. These expectations, as outlined in the sick role, are that: 1) As soon as a person realizes they may be sick they visit a doctor or other medical provider; 2) The person receives a diagnosis; 3) The person receives a course of treatment and strictly follows that treatment; and 4) The person wants to recover and return to society and ultimately achieves this goal (Parsons, 1951).

The Sick Role

My first research question was designed to explore whether or not the elements of the sick role were, in fact, present in participants' narratives of Fibromyalgia Syndrome. If they were, I wanted to explore the ability of people with Fibromyalgia to fulfill the sick role, and the results of this successful or unsuccessful negotiation on the other parts of their lives. Existing literature supported my suspicion that people with Fibromyalgia Syndrome would, indeed, attempt to fit their experiences into the steps of the sick role (i.e. Garro, 1994; Glenton, 2003; Robinson, 1990; Werner, 2004). For instance, both Garro and Robinson suggested that almost all people with an illness will attempt to follow the sick role without considering whether or not it is fully applicable to their situation because the sick role is in many ways the only socially accepted and allowable script for illness behavior. As Garro (1994) noted, cultural models such as the sick role provide us with "guidelines for perceiving, organizing, interpreting, representing, making inferences about, and acting in the world (p. 786). Therefore, I believed that participants

in this study would implicitly attempt to follow the sick role script despite the difficulties they may have in doing so.

In order to explore this belief, I began by looking carefully for the influence of the sick role in the narratives of participants. In doing so I found that participants were guided by the sick role script despite the potential problems they could face in trying to adhere to that script. For instance, participants knew the importance of receiving an actionable diagnosis. Their stories reflect this knowledge in that many participants continued to search for a diagnosis for months and even years despite their lack of success. Moreover, participants in this study not only waited for extended periods of time for a diagnosis but also knew that they were responsible for initiating and re-initiating the process of receiving that diagnosis. Similarly, sick role theory suggests that once a person feels ill, their main responsibility is to seek prompt medical advice. Participants in this study were also aware that they were expected to recover from Fibromyalgia, and indeed making a full recovery is one of the final steps in the sick role. As Glenton (2003) noted, it is important for chronic pain sufferers to go through a successful medical treatment plan. In addition to the potential of pain relief, this process also indicates a patient's willingness to cooperate with doctors and "proves" that the patient's pain and suffering has been sanctioned by a medical authority and therefore must be real (Garro).

However, despite participants' awareness that they *should* recover from Fibromyalgia, many also knew that they *probably would not* recover and this knowledge was problematic in terms of following the sick role. For instance, when I asked most participants specifically if they felt that Fibromyalgia could be cured, nearly all said no. For example, DJ said, "I wish I could wake up tomorrow and [my Fibromyalgia] would be gone. But it's not going to happen." As a result, it became clear that although participants were aware of the expectations outlined by the

sick role, and made efforts to fulfill those expectations, many would ultimately fail in their efforts. As Mechanic and Volkart (1961) observed, “the desirability of the sick role, under various conditions of stress, may motivate persons consciously or unconsciously to seek its protection” regardless of whether or not they will actually be able to attain that protection (p. 52).

Failure to Fulfill the Sick Role

After determining that the narratives of participants in this study were, indeed, influenced by the sick role, I set out to explore the second part of that research question: Were participants able to fulfill their sick role obligations? As the themes and stories in Chapter 4 quickly revealed, participants were not able to fulfill the sick role despite their desire to abide by its guidelines. Therefore, the following sections will explore *why* participants in this study were unable to fulfill the sick role. These reasons are: 1) FMS symptoms are difficult to understand; 2) FMS is not a ratified or respected diagnosis; and 3) participants’ typically become actively involved in their diagnosis and treatment which makes it even more difficult for them to access the sick role; and 4) There is no cure for Fibromyalgia and therefore participants cannot exit the sick role process.

Problematic symptoms. The primary barrier to sick role fulfillment faced by participants in this study was that the symptoms of FMS do not fit the pattern of normative illnesses. While expectations based on the sick role call for clear, quantifiable, and consistent sickness markers, FMS violates each of those terms. To begin, no objective biological markers or diagnostic tests can verify the presence of FMS (i.e. Barker, 2002; Henriksson & Burckhardt, 1996). In part this lack of reliable diagnostic testing is related to the fact that most patients’ primary complaint is pain, and pain cannot be measured or tested. As a result, participants in this study had to prove the existence of their pain by convincing their doctors, friends, and family that what they felt was real. As Glenton (2003) noted, “it is not the physical characteristics of back pain that represent

the greatest threat to back pain sufferers' social status, but a suspicion that the pain does not really exist" (p. 2249). The invisible, unquantifiable, and subjective nature of participants' symptoms denied many of them the social support necessary to fully claim the sick role and being completely released from their regular duties so that they could focus on recovery.

Further complicating matters was that FMS symptoms are often inconsistent as patients may experience flare-ups one week and relatively normal health the next. However, doctors are trained to look for clear tests results and consistent symptoms when providing diagnoses. Moreover, as Glenton (2003) explained, these same doctors are "key players" and serve a "gatekeeper function" in the legitimation of illness (p. 2244). As Zoe, a focus group participant explained, "You need to continually have these symptoms for a long time" in order for a doctor to give you a Fibromyalgia diagnosis. The prerequisite that a patient must experience consistent symptoms before receiving a diagnosis was particularly difficult for many participants in this study, and as a result the vast majority not only struggled for acceptance from their families and friends, but also went months or years without a firm diagnosis from their doctors. This lack of diagnosis meant that participants also lacked the sort of official medical backing they needed to claim the sick role, which fed the cycle of social rejection. After all, just as there is an assumption that anyone who is suffering should receive medical care, there is also an assumption that if doctors cannot provide care, then a person is not really sick (Glenton, 2003).

A problematic diagnosis. Once participants in this study did receive a diagnosis of Fibromyalgia, they were still often unable to continue on to the next steps of the sick role: successful treatment and return to normal life. Their stories, combined with the literature, suggest two main reasons for their continued struggle. First, Fibromyalgia is not a respected or understood diagnosis within the medical community or society at large (Barker, 2002;

Henriksson & Burckhardt, 1996). Participants themselves knew that their diagnosis was problematic. For instance Billie G. referred to people's perceptions of Fibro as a "flaky, bizarre condition no one knows anything about." As a result of this nonratified status, a Fibromyalgia diagnoses did not guarantee participants the same level of understanding and respect that is afforded to people with ratified illnesses such as influenza or diabetes. Without this understanding and respect (i.e., societal acceptance) participants could not progress within the sick role as they did not have the social ratification to do so (Stewart & Sullivan, 1982).

The second reason that an FMS diagnosis did not help participants access the sick role was that Fibromyalgia often encompasses both mental and physical symptoms, and yet the sick role is designed to address physical symptoms alone (Glenton, 2003). In particular, the sick role protects people from being held responsible for their physical symptoms; however, people with signs of mental illness may find that friends, acquaintances and even medical professionals question the reality of their symptoms. For instance Sandy, an interview participant, recalled that when she was first diagnosed with Fibromyalgia her immediate response was, "Ugh! Not good! People are going to think I'm crazy or something!" This tension between physical (real) symptoms and mental (imaginary) symptoms reflects the larger tensions inherent in the concept of mind/body dualism (i.e. Glenton, 2003; Segall, 1976). Although a full exploration of mind/body dualism is beyond the scope of this study, it is important to note that it is an appropriate way of understanding the sick role in that the sick role is designed with physical (i.e. "real") sickness in mind and does not have a place for mental (i.e. "imaginary") illness (Glenton, 2003). This distinction has the potential to exact very real consequences for Fibromyalgia patients because, as Glenton noted, when diagnostic tests continue to come up empty as they do in the case of Fibromyalgia, some health professionals may turn to psychological explanations

for chronic pain. Moreover, many participants in this study did have psychological symptoms, such as depression or anxiety, accompanying their physical pain and fatigue. Nevertheless, all participants knew that their pain was real and should be treated regardless of the other symptoms they experienced. As a result, diagnoses of *only* depression or anxiety were frustrating for these patients who felt that their physical symptoms were being dismissed or misunderstood.

Moreover, part of participants' frustration with receiving diagnoses which were limited to mental illness was that our societal script suggests that mental illnesses are in part caused by, and therefore must in part be controlled by, patients themselves whereas physical illnesses are out the patient's control (Glenton). This means that people with perceived symptoms of mental illness are held to a different standard than people with purely physical symptoms of illness. As Segall (1976) explained,

In the case of a physical condition, the situation is relatively clear. Something is wrong with the individual's physical functioning (for which he is not responsible), and he should consult a physician as soon as possible. However, when the condition also has psychological connotations, the question of personal responsibility arises. To what extent is the individual responsible for both causing and coping with mental illness? (p. 164).

As a result, patients with psychological illnesses have an even weaker claim to the processes outlined in the sick role. Indeed, as Segall (1976) also noted, "the mentally ill individual not be exempted from all of his social responsibilities while he tries to get well" (p. 164). Instead, and in direct contrast to the expectations of the sick role, "the psychiatric patient is generally expected to be active, independent and self-directed in interacting with his doctor" (Segall, p. 164). Therefore, FMS patients cannot fully claim the sick role because their actual, or assumed,

symptoms of mental illness preclude them from a model which embraces only physical signs of disease.

Reacting with agency. As a result of their frustration, lack of progress, and continued symptoms, many participants took charge of their progress by searching out doctors, treatments, and information on their own. As Stewart and Sullivan (1982) noted, “patients will reject physicians’ diagnoses and treatments when they appear ineffective to them” (p. 1403). This was certainly true for Aimee, a young interview participant, who explained that when she was first diagnosed she, “didn’t have the Internet at home and I just trusted the doctors until [the Fibromyalgia] became so bad, so badly nasty on my body.” However, while taking control of their diagnosis or treatment may have felt better for many participants because it allowed them a form of control over their situation, agency and empowerment was also another mark against their claim to the sick role as it is in direct violation of the passivity the sick role requires (Stewart & Sullivan). As Segall (1976) noted, patients are expected to cooperate with their own doctors by being passive, submissive and generally dependent. As a result, the participants in this study were left in a very precarious social position wherein they sought entry into the sick role to relieve their physical and social symptoms, but as they could not fulfill its requirements, they often took control of the process in ways that inevitably resulted in further stigma and denial of the sick role.

Lack of a cure. The final reason that FMS patients cannot access the sick role is that there is no cure for FMS; and yet the sick role requires that a person recover from their illness and return to their normal roles within society (Arluke, Kennedy, & Kessler, 1979; Crossley, 1998; Parsons, 1951; Shilling, 2002). This barrier inhibits not only Fibromyalgia patients but also many other patients with chronic illness. For instance, for patients in Garro’s (1994) study

who finally received a diagnosis of Temporomandibular Joint Syndrome (TMJ), the initial feeling of relief “was sometimes followed by disillusionment if treatment did not lead to improved health” (p. 779). This likely occurs because, as Glenton (2003) suggested, there is no socially appropriate method of dealing with the constant symptoms inherent in chronic pain conditions. Although in the acute model of sickness taking sick leave from work or being prescribed pain pills is acceptable because it is a short term remedy, the “use of these strategies over longer periods of time and with no apparent improvement can be interpreted as a sign of weak will” (Glenton, p. 2250). As Butler (1970) explained, “a social system cannot for long afford an endemic or epidemic adopting of the sick role” (p. 243). Therefore, it is not socially acceptable to be sick for an extended period of time because if everyone in society were to behave that way, it would result in the breakdown of social norms and roles. As a result, the sick role’s function of isolating people with illness and ensuring that they want to recover reduces the risk of “formation of a deviant sub-culture” of illness (p. 243). However, these mechanisms also mean that people with chronic illnesses, such as FMS, are prevented from accessing the sick role in part because they will not be able to leave that role.

Ramifications of Exclusion from the Sick Role

The previous two sections lead to the final component of my first research question: If people with Fibromyalgia do attempt to fulfill the sick role, but fail in doing so, how does that failure impact their daily lives? As the narratives and themes from Chapter 4 suggest, participants in this study experienced social stigma and psychological pain as a result of their failure to fulfill the sick role. Moreover, they were either denied the tangible benefits of the sick role, such as sick leave or disability pay, or feared that those benefits could be taken away at any moment.

As I suggested previously, sick role theory not only outlines a list of steps that people with sicknesses must follow, but it also dictates that if people successfully follow those steps they will receive certain protections and privileges (Glenton, 2003). Most notably, sick role protections include the absolution of responsibility for one's condition, a socially-sanctioned break from one's social responsibilities, and general agreement that one is sick and is genuinely working to recover (Arluke, Kennedy, & Kessler, 1979; Crossley, 1998; Parsons, 1951; Shilling, 2002). These protections are necessary because, as Miczo (2004) noted, "illness can pose a burden to those around [the ill individual]" and moreover people are aware that "some illness behavior can be intentional and for the purpose of secondary gains" (p. 357). As a result of the nature of their symptoms, Fibromyalgia patients in particular need these protections so that they are not accused of making up their illness. However, participants in this study were unable to fit their FMS experiences into the script outlined by the sick role, and as a result, they were denied these protections and often faced social stigma. In fact, the literature suggests that this stigma may be worse for people with ambiguous chronic conditions like FMS because these conditions tend to result in "social dissensus and disharmony" as a result of being "less normatively controlled" than standard acute conditions (Stewart & Sullivan, 1982, p. 1403).

This lack of social protection carried with it very real consequences. For instance, Glenton (2003) found that the people with chronic back pain who participated in her study expressed concern and even fear related to the degree to which their pain was validated and accepted by healthcare professionals, family, and friends. Similarly, participants in this study also feared social retaliation, and in many cases their fears were warranted. For example, the story of Amelia Carter, a young MBA just starting out in her job, highlights the experiences of many participants with full-time jobs. Amelia, like many people with Fibromyalgia, missed a lot

of work and experienced periods of low productivity related to her condition. However, because her diagnosis was misunderstood by her coworkers, she was ostracized and the legitimacy of her illness was openly questioned. Her coworkers insinuated that she was lazy or simply uninterested in her job, when in fact Amelia was trying to balance her need and desire to work with her ability to do so. Similarly Grammy, a middle-aged grandmother who still works full-time, explained that no one takes Fibromyalgia seriously “Unless you wear a sign around you that says [that you’re sick], or, I guess in a way I do because I’ve become a real witch [to my coworkers and friends] in the last two years.” As Grammy’s story indicates, the lack of sick role protection can result in social isolation and stigma. In this way, some participants isolated themselves and condemned others in an attempt to avoid forcible isolation or condemnation.

It follows, then, that participants in this study also experienced shrinking social worlds as a result of Fibromyalgia (i.e. Reynolds et al., 2008; Stewart & Sullivan, 1982). For instance DJ, a retired grandmother and interview participant, said, “There are people who understand and there are people who don’t and then there are people who *say* they understand, who don’t.” Like many other participants, DJ lost some friends altogether, and no longer makes long-range plans with her remaining friends because she needs to cancel so often that she feels unreliable. Similarly Johanna Donne, a focus group participant, spoke about making up non-Fibromyalgia-related excuses for why she could not attend late dinners with friends or other long social events in the evenings because she was embarrassed to continue providing the same explanation of Fibromyalgia-related fatigue. Likewise Dina Kelly, a character in the synthesis stories, also reflects the social difficulties that participants faced in remaining friends with people who do not have Fibromyalgia. Like a few others in this study, Dina made up for her lost friends by attending support group meetings. She explained, “I like having a social life with people who

understand that some days I don't feel well enough to be there or other days I may not say much because I'm in too much pain, but I'm still enjoying their company.”

The psychological pain of delayed diagnosis. Participants in this study also experienced a certain amount of worry, fear and anxiety as a consequence of not being able to fulfill the sick role. After all, following the sick role results in a certain level of comfort and predictability as patients know what to expect, and are able to progress through their illness process in a somewhat anticipated way (i.e. Garro, 1994; Kugelmann, 1999; Reynolds et al., 2008; Stewart & Sullivan, 1982). Conversely, however, the experiences of participants in this study suggest that the inability to do so may result in psychological discomforts including frustration, fear, depression, tension, and worry. A moment during one of the focus groups reflected these negative psychological outcomes when Zoe, a middle-aged and energetic participant, thought back to waiting years for her diagnosis and recalled, “I began to think I had MS or something...and I didn't want to say anything about it and...this stupid Internet doesn't help any!” As Zoe illustrated, many participants in this study feared the worst when they started experiencing symptoms and could not receive an immediate diagnosis. They would scour the internet and worry about, or even be tested for, diseases ranging from cancer to AIDS to Multiple Sclerosis. The synthesis stories I created also mirrored this anxiety and fear. For example, the character Dina Kelly, in a moment based on an actual participant, was told she could have polio. Similarly, the character Amelia Carter was tested for AIDS and lupus. These kinds of experiences created a great deal of fear and anxiety for participants, such that in some cases being diagnosed with *just* Fibromyalgia was something of a relief after months or years of not knowing what was wrong.

Tangible benefits. In addition to experiencing negative social and psychological consequences for failing to fulfill the sick role, participants in this study were also at risk of losing the kinds of tangible benefits given only to those with confirmed chronic illnesses, in particular disability insurance (Glenton, 2003). Although most participants in this study were not receiving disability pay as it is difficult to do so in the United States, the few who were seemed worried about their futures. For instance, Billie G., an interview participant, explained that,

Billie G.: With just now being on the disability sometimes I think, ‘Well what if somebody sees me out there cutting my grass? I mean am I gonna lose my disability?’ ‘What if...and it’s invisible, people can’t tell that there’s something wrong with you and so...when I first started having changed the things I did and say no to things that I would have otherwise said yes to, I really felt like, I was very self-conscious about it, people are going to think I’m lazy.

Megan: Because you look the same?

Billie G.: Yeah, yeah, and they don’t know how hard it is for me to do some of these things.

Billie G.’s concerns are also interesting because they meld her fears about the social consequences of her illness with her fears about the tangible benefits she could lose as a result of people’s misunderstandings.

Leisure-based Self Care

The second primary focus of this study was to explore the types of leisure-based self-care practices, including coping mechanisms, that used by participants in this study. Moreover, I wanted to understand the effects of these practices on the daily lives of participants. Previous

research (i.e. Coleman, 1993; Kleiber et al., 2002; Robinson-Smith et al., 2000) has hinted that leisure may be very important in the lives of people with nonratified chronic illnesses like FMS; however, little to no research has looked specifically at FMS. Therefore, part of the design of this study included an exploration of the roles of leisure in the lives of people with Fibromyalgia Syndrome. In doing so I found that, for participants in this study, leisure, particularly leisure-based self-care, including coping, was a very important part of daily life. Moreover, participants utilized a wide variety of leisure-based self-care measures to help treat their symptoms, either as an alternative to traditional medical care or as a compliment to it. These measures included, yoga, walking, swimming, art therapy, acting, weight lifting and bicycling. For instance Penny, a support group leader and focus group participant, talked about practicing “I-Chi” which she explained as Thai Chi performed in a swimming pool. She clearly thought of I-Chi as a legitimate Fibromyalgia treatment and mentioned that she regretted that her insurance company did not cover it as such. Robin Merriwhether, a middle-aged interview participant, had developed her own stretching and exercise routine that she performed each night before bed. She was certain that if she did not follow this routine, she would feel even worse. Similarly Billie G., an interview participant and cancer survivor, said that general physical activity, such as yard work or walking, was one of the best ways to treat her Fibromyalgia Symptoms as long as she did not overexert herself. John Brennan, an interview participant and father of young children, also emphasized the importance of an exercise routine as part of Fibromyalgia treatment. He explained, “I think [exercise] is probably the main thing to do [so that you don’t] sort of shrivel away and just kind of sit there because it feels good not to do exercise or not to go and do yard work.” Similarly the characters in the synthesis stories also reflected participants’ emphasis on leisure-based self-care. For instance, Dina Kelly and Nicole Andrews talked about the

therapeutic value of art, a topic that came up frequently during one of the focus groups. Similarly Dutch Sanderson's methodical search for triggers also included a search for self-care tactics that would help her feel better. Like many participants in this study, Dutch found that yoga and general light stretching helped to relieve some of her discomfort. As the above examples demonstrate, leisure played an important and very utilitarian role in the lives of participants in this study. In particular participants chose specific leisure activities and put them to work either as complimentary or alternative treatments for Fibromyalgia.

As an alternative to the sick role. The current study also suggests a clear link between participants' use of leisure-based self-care, and their failure to access the sick role. FMS patients experience a great degree of difficulty fulfilling the sick role for all of the reasons outlined previously, in particular the fact that the sick role requires official medical treatment and discourages patient agency. Therefore, Fibromyalgia patients who want effective treatment or even a cure for their illness are often unable to pursue those ends through in any recognized or socially-sanctioned way. As a result, the current study suggests that leisure-based self-care may help Fibromyalgia patients feel that they *are* able to move towards the sick role's goals of societal recognition, effective treatment, and recovery and return to normalcy, even when those goals are not attainable through the official sick role process. This suggestion is the main theoretical implication of the current study; moreover, previous research has not linked leisure and the sick role in any meaningful way.

The association between the sick role and leisure-based self-care is clearest in the overarching course of many participants' narratives. For instance Sarah, an interview participant who considered herself cured after 10 years with Fibromyalgia, structured her narrative in such a way that made clear links between the failure of medical doctors to provide a cure and her

initiation of leisure-based self-care measures. Specifically, she explained that she went through the usual prolonged diagnosis period only to be sent to a doctor who told her that her Fibromyalgia would never be cured, but that her symptoms could be managed with pain medications. Sarah rejected this doctor's assessment, believed that she could be cured, and therefore visited doctor after doctor until she found one that was willing to endorse the leisure- and lifestyle-based treatment plan that she herself had created. Similarly, Niki Blackstone's narrative was also focused on rejecting traditional medicine in favor of alternative treatments (i.e. massage, vitamins, and leisure-based treatments). Niki also insisted that her Fibromyalgia could be cured, and as a result she chose only to work with medical professionals who both supported this idea and who would also support her leisure- and vitamin-based treatments. Niki and Sarah had particularly interesting relationships with medical authority in that they both sought official endorsement for their treatment plans, but nevertheless rejected doctors who approached Fibromyalgia (or patient agency) in a more traditional manner.

Other participants who had more standard relationships with their doctors also seemed to utilize leisure-based self-care as a method of circumventing the sick role process. For instance, Penny, a focus group participant and support group leader, has dedicated much of her leisure time to understanding and treating her Fibromyalgia symptoms even though she rejects the idea that Fibromyalgia can be cured. In particular she participates in I-Chi exercises, takes art therapy classes, and leads a social support group all dedicated to understanding and treating Fibromyalgia outside of the medical system. It is Penny's hope that these activities will provide the kind of relief from her Fibromyalgia symptoms that her doctors have been unable to provide and therefore allow her to access the "treatment" phase of the sick role outside of the official medical system. Moreover, Penny's support group activities may also help her, and the other

participants in her group, achieve the social recognition and acceptance that is required by the sick role but so often denied to Fibromyalgia patients because of the unrati ed nature of their illness. The end goal of these plans is the same as the final step of the sick role: to recover from Fibromyalgia and return to normalcy.

As the above examples illustrated, the meta-narratives of participants in this study suggest that leisure-based self-care may provide an alternative framework for accessing some of the key benefits of the sick role when direct access to the sick role is denied. In particular, participants may be able to use leisure spaces and activities to create alternative social networks which provide support and ratification, a space to experiment with alternative or complimentary treatments, and even help working towards recovery.

Hope and Empowerment. An interesting and noteworthy side-effect of utilizing leisure-based self-care as an alternative to the sick role is that doing so also provided participants with a forum for developing agency, empowerment, and even hope. As Kleiber et al. (2002) noted, “restorative experiences” and “small successes” such as those experienced during self-care can help to “facilitate hope and the appreciation of new opportunities” as well as assist in “alleviat[ing] depression” (p. 224). Likewise, Son and Hutchinson (2009) suggested that leisure self-care is “less about managing one’s limitations and problems” and more about providing people with an arena in which to go through the processes of expressing abilities, strengths and interests with the goal of creating healthy outcomes (p. 27). In particular they suggested that finding new ways to provide self-care can lead to a new and more empowered identity. Similarly, Stoller et al. (1993) acknowledged that it takes a certain amount of agency to provide self-care, and therefore they suggested that, “if a symptom can be alleviated through some lay action, people’s sense of mastery may be enhanced and the threat associated with the symptom

diminished” (p. 37). Likewise, Reynolds et al. (2008) reported that people with Chronic Fatigue Syndrome who engaged in self-care actions experienced improvements in their subjective well-being.

The stories of participants in this study do seem to speak to the ability of leisure to provide hope and empowerment, particularly in the face of difficulties related to sick role expectations. For instance DJ, a grandmother and interview participant, talked about the therapeutic value of playing with her grandchildren. She explained, “I don’t want to become Fibromyalgia. It isn’t who I am.” Her leisure time with her family helped her claim other, more valuable, identities such as active grandmother or caring mother. Similarly several of the synthesis stories reflected the experiences of many participants who spoke about the empowering value of leisure-based self-care. For instance Dina Kelly talked about an art therapy class she attends and said, “It just feels good to be able to create in the face of pain,” a sentiment shared by the study participants who engaged in art therapy. Likewise Dutch Sanderson reflected the experiences of participants who look to exercise to help them treat their pain and fatigue. Her diary entries illustrate the empowering affects of being able to take care of herself and treat her own symptoms.

Coping. In addition to leisure-based behaviors designed specifically to relieve the symptoms and side-effects of Fibromyalgia, participants in this study also provided self-care through coping. Indeed, a well-developed body of leisure research suggests the importance of leisure as a tool for coping with negative life events, such as the onset of injury or the continued course of a chronic disease. As Kleiber et al. (2008) suggested, in these situations even the simplest leisure activities may play powerful roles in people’s lives by providing distraction as well as an arena for social interaction. Similarly Hutchinson et al. (2003) stated that leisure during times of hardship may, “serve as a coping resource by buffering the impact of negative life events through

distraction, generating optimism, and enabling individuals to preserve a sense of self” (p. 144). Likewise Iwasaki (2006) found that, “a meaningful leisure pursuit potentially provides [people] with an opportunity for gaining some sense of control” (p. 217). Moreover, Iwasaki went on to suggest that, “the role of leisure in coping with stress may be particularly more relevant and essential to marginalized groups than to less marginalized groups” (p. 217). Within the context of the current study this may be taken to mean people who are marginalized by their experiences with FMS.

Indeed coping, particularly leisure-based coping, did play an important role in the narratives of participants in this study for many of the reasons mentioned previously. For example both DJ, a grandmother and interview participant, as well as Aimee, a young interview participant, read novels as a means of escaping their daily lives with Fibromyalgia and finding peacefulness and alternative realities. These books allowed them to focus on things that made them happy and distracted them from the work involved in Fibromyalgia Syndrome. Similarly Amy, a middle-aged woman and focus group participant, found her escape in humor and made a habit of reading the newspaper comics every night before bed. She explained that she was inspired by Norman Cousins who, she explained, “locked himself in a room and rented all kinds of funny movies” while he was going through cancer treatments. Amy concluded, “I think that’s very important.” Indeed Kleiber et al. (2002) suggested that these kinds of escapist activities lead to hope and therefore play a very important role in the lives of people with chronic illness or injury. For this same reason, Hutchinson et al. (2003) called escapism a “self-protective form of leisure.” Similarly Kleiber et al. suggested that, “patterns of activity that are apparently avoidant may [in fact] create the space necessary for hope and optimism” (p. 226). They suggested that hope and

optimism results because, “in creating some room through distraction, control is restored to some extent and alternative possibilities are envisioned” (Kleiber et al., p. 227).

Participants in this study also used mental toughness to cope with their Fibromyalgia symptoms. For instance John Brennan, an interview participant and father of two young children, explained that he tries to carry on with life as usual and, for the most part, works to block out the pain. He explained, “I try not to pay attention to the pain [...] because even when I don’t feel like the Fibro’s bad, if I sit there and think about how my body feels, it doesn’t feel good.” Similarly participants in Reynolds et al.’s (2008) study indicated that at times they were willing to exceed their physical or mental limits in order to engage in leisure activities they enjoyed. Likewise Hutchinson et al. (2003) found that it was especially important for participants in their study to remain involved with familiar activities after the onset of a traumatic injury or illness. They explained that, for these participants, familiar activities were particularly important elements of the coping process especially “if they provided a sense of connection with one’s past and affirmed personal values and beliefs” (p. 157). This was certainly the case several participants in this study who chose to continue with activities that they felt were important parts of their family lives despite the fact that these activities caused them increased pain and fatigue. As a result, developing a sort of mental toughness that allowed for the continuation of favorite leisure activities was an important coping resource for participants in this study.

Moreover, in addition to “toughing it out,” participants also coped with their illness by seeking out activities that were purely enjoyable and served no other real purpose. For instance, John Brennan enjoyed yoga not because it helped his symptoms but because it helped him have fun in his body instead of only experiencing his body as a source of pain. Similarly, DJ had so

much fun volunteering for the 2008 presidential election that she was inspired to engage in more activities simply for pleasure. She said, “I keep hoping [my best friend and I] are going to explore more, [go to] the basketball games or whatever, get out there and have fun.” Likewise Robin Merriwether, an interview participant, loved to garden and even once she was diagnosed with Fibromyalgia and her leisure time became complicated due to pain and fatigue, she chose to keep gardening. She deemed her garden a “list-free zone” and explained, “I do not make any attempt to prioritize or make lists or do things in a logical order or any of that, I just totally do what I feel like [when I’m in my garden].” She continued, “[My garden’s] just my play area, so that’s a nice thing.” In this way several participants were able to experience pleasure, joy and happiness despite the hardships of their illnesses.

Research indicates that these outcomes are important aspects of self-care. As Kleiber et al (2002) stated, “The potential for leisure to generate positive emotion may give it a special role in facilitating effective coping and adjustment in the wake of a negative life event” (p. 224). Furthermore positive leisure experiences, particularly coping mechanisms, may help people “to carry on with hope and appreciation for life itself” (Kleiber et al., p. 231).

Participants in this study also discussed the importance of social activities in helping them cope with the impacts of their illness. This finding is similar to the experiences of participants in Hutchinson et al.’s (2003) study who indicated that shared activities, or what Iwasaki and Mannell (2000) called “leisure companionship,” were very important as they contributed both to feelings of normalcy as well as providing a sense of belonging. This sense of belonging and understanding was also important for participants in this study. For instance Penny led a local Fibromyalgia support group and as a result she had a small group of friends who really understood her illness. She spoke about the importance of these friends by telling a story about

having one of her support group friends over for dinner. Penny had a flare-up that night and remembered the relief she felt when her friend could tell that she was in pain, accepted that her pain was real, and chose to leave early instead of make it a late night. DJ, a retired grandmother and interview participant, also valued social relationships and felt that social time helped her cope with her FMS. In particular, she spent several days a week at her daughter's house babysitting her grandchildren and spending time with her daughter. This time helped her feel closer to her family and reinforced the importance of her roles as mother and grandmother. However, these stories are something of an exception because in general participants' social lives suffered considerably as a result of Fibromyalgia. Therefore, while many participants valued and sought out social leisure, few were able to participate in it at the level they would like.

As the above examples illustrated, leisure-based coping played an important role in participants' lives. In particular leisure-based coping allowed for an escape from pain and hardship as well as the ability to continue favorite activities. Moreover, leisure provided a time and space for pure fun and enjoyment. Each of these roles was important for participants' quality of life and ability to provide self-care.

Constraints

The final research question guiding this study was designed to explore participants' experiences with constraints, particularly leisure-based constraints, and their ability to negotiate those constraints. In exploring this question I found that, despite the positive roles of leisure in the lives of participants and their ability to participate in various types of activities, nearly every participant also experienced severe and at times non-negotiable constraints related to their Fibromyalgia symptoms. As Kleiber et al. (2002) noted that, "disruptions of roles, relationships, preferred activities, and even attitudes toward the future are to be expected" following negative

life events (p. 220). Similarly Hutchinson et al. (2003) noted that, “as a consequence of a chronic illness or traumatic injury, people may encounter challenges to maintaining daily routines [as well as] changes in relationships, roles, and physical abilities” (p. 145). Similarly Hensing et al.’s (2007) study of neuropathic pain noted that chronic pain had an unexpectedly profound effect on patient’s social lives, and that pain-related constraints affected patients work, leisure and family activities (p. 152). Finally, Richardson and Ream (1997) found that tiredness and weakness are often the two symptoms that interfere most with patients’ lives. As the participants in this study experienced the onset of a negative life event (Fibromyalgia) as well as experienced chronic pain, weakness and tiredness, it is not a surprise that they also experienced significant constraints to engaging in everyday activities, including leisure. For instance, Rose Turner, a focus group participant, explained, “I can’t do as much [since the Fibro started], I can do, but I can’t do as much.” Similarly Grammy, an older interview participant, estimated that she had stopped doing 99% of her previous activities. She explained, “I used to do 5K races, walking and running. I used to take care of some horses and all that’s involved with cleaning them up, but I haven’t been around horses in I don’t know how long. I just kind of, I went from being less than 50 years old in 2008 to being a 90 year old now.” Niki Blackstone, a middle-aged energetic doctoral student and interview participant, has also given up a lot since the onset of her Fibromyalgia symptoms. She explained, “I stopped doing any kind of hand craft stuff like I used to. I don’t iron. I don’t cook. I don’t work in the garden. I have a bunch of plants that are going to die because I can’t get them in the ground.” In addition to activities that participants had to give up, daily life necessities like sitting still were also difficult. For instance many participants spoke about the difficulties they faced in sitting through movies or going on airplane or car trips because sitting still for extended periods of time was painful. For example, Johanna

Donne, a focus group participant who loved to travel, spoke about the difficulties she faced on transatlantic flights. She explained that while her physical therapist has instructed her to stand up frequently during flights, the aisles are not wide enough and post-911 security makes it even more difficult.

Yet despite these difficulties, participants were able to find some ways around the constraints they faced. The primary way that participants navigated their constraints was by making choices about how to spend their limited energy or how much pain to tolerate for any particular activity. LeAnn Bryant, a middle-aged focus group participant, explained, “Someone told me, I don’t remember who it was, but somebody said, ‘Sometimes it’s just worth it, the pain’s worth it, because you’ve got to do things that you have decided that you’re going to do.’” Similarly DJ, a grandmother and interview participant said, “I made a conscious decision, ongoing, which things I will do knowing that I’m going to pay for it and which things aren’t worth it. And my grandchildren usually win out. It’s like [if my choice is to] carry [my granddaughter] to bed or [not] to, I’ll carry her to bed, even if I know the back or the neck is going to hurt the next day.” By making careful choices about which activities were worth pain and fatigue and which were not, some participants were able to continue doing some of the activities they felt strongest about.

In addition to making choices, participants also modified activities so that they could continue to participate. For instance, Johanna Donne, a focus group participant who liked to go for bicycle rides, purchased a recumbent bike and got rid of her regular upright bike because she found that the recumbent bike was more comfortable and allowed her to ride despite her joint pain. Indeed many participants used aids to help them modify their favorite activities. For instance some walked with canes so that they could avoid using wheelchairs when their knee

pain flared up, and others bought special walking shoes so that walking, both for exercise and as part of daily life, would be less painful. Finally many used heating pads or hot water bottles to help them sit still for extended periods of time or sleep on hotel beds so that they could travel.

Still other participants negotiated their constraints by substituting less Fibro-friendly former activities with new, more “Fibro-friendly” activities. For instance, Robin Merriwhether, a phone interview participant who is on disability as a result of her Fibromyalgia, found that she could no longer participate in her evening book club both because of the late hour and because her Fibro Fog prevented her from being able to read and retain information the way she used to. As a result, she gave up her book club in favor of the bell choir at her church. She explained that the bells suited her because she did not have to memorize any notes or read music particularly quickly. Moreover, she was able to interact with others and thereby gain some social support as well.

As the above examples illustrated, the participants in this study faced significant constraints as a result of their FMS symptoms. While many participants were able to negotiate some of those constraints, most participants experienced an overall reduction in their leisure repertoires.

Chapter 6 – Conclusions

The main goal of this study was to gather narratives from people with Fibromyalgia Syndrome (FMS) in order to shed light on the sick role within the context of Fibromyalgia Syndrome. I also wanted to further explore the relationships among self-care, constraints and leisure for people with nonratified chronic illness. The results of this study indicated that sick role theory is an important and necessary component in understanding the behavior of people with chronic illness, and yet the theory is underutilized in modern work with chronic illness populations. Moreover, the experiences of participants in this study suggested several interesting theoretical linkages between leisure and health, primarily the ability of leisure-based self-care to provide a working alternative to the sick role. This suggestion has not been previously explored. Finally, the recommendations of participants themselves create opportunities for medical and leisure professionals to implement practical programs that will have measureable positive impacts on the daily lives of people with Fibromyalgia Syndrome.

Theoretical Implications

The experiences of participants in this study indicated that they had a strong desire to follow the sick role script despite the low likelihood of being able to do so successfully. In particular, the very nature of Fibromyalgia as a chronic, intermittent, un-testable, and untreatable illness made it difficult for participants to progress from diagnosis to treatment, and the chronic nature of FMS made it impossible for them to progress from treatment to recovery. Nevertheless, participants' narratives illustrated their aspirations to receive the benefits of the sick role even if they could not access it appropriately. The benefits they sought included societal acceptance of their illness, a meaningful diagnosis, effective treatment, and an eventual recovery/return to normalcy. As a result, the results of this study are able to assert that the sick

role theory is not only applicable to understanding the experiences of people with chronic illness, but may in fact be crucial for doing so in that people with chronic illness are unable to fulfill the sick role and therefore may experience social and psychological ramifications different from those experienced by people with acute and temporary illness. As a result, the experiences of participants in this study suggest that applying the sick role to future studies of illness behavior would greatly strengthen our understandings of the interactions between individuals and society in the case of chronic illness.

Leisure-based self-care. Moreover, despite clinical definitions of FMS as chronic, participants in this study differed in their beliefs about the permanence of their condition. In particular a small minority felt that they could eventually recover using leisure-based self-care whereas others felt that they could at least utilize leisure-based self-care to effectively manage their symptoms until a cure for FMS is discovered. As a result, leisure-based self-care played a vital role in the experiences of many participants. In fact, the current study suggests specifically that leisure-based self-care may function as an alternative to the sick role by helping patients attempt to access some sick-role related benefits such as effective treatments or even a cure. While the societal expectations inherent in sick role theory still impacted participants' experiences, the actions they took via leisure-based self-care provided them with a level of agency and success that they would not have otherwise experienced. Therefore, future studies of the sick role from a leisure science perspective should further theorize the applicability of leisure-based self-care as a working alternative to the sick role steps. In particular, there is room for the creation and testing of a model suggesting alternate pathways for people who cannot access the sick role using the traditional set of sick role steps.

Agency. Previous research has not linked agency, the sick role, and leisure-based self-care in this way, and yet many participants in this study needed to have a certain amount of agency in order to utilize leisure-based self-care as an alternative to the sick role. For instance, many participants conducted their own research regarding FMS treatments, and then created personalized treatment plans based on what they discovered. Doing so required participants to have a certain level of empowerment as well as the confidence to take their health into their own hands. However, while it may seem that nothing bad could come of agency and empowerment in this context, an examination of the literature combined with the experiences of participants in this study indicates that this kind of agency in an illness context is something of a double-edged sword. In particular, while empowerment and agency propelled participants in this study to be able to take care of themselves, and allowed them to utilize leisure-based self-care to seek the protections normally provided by the sick role, this same empowerment and agency were further marks against participants who were trying to access the sick role. As previous sick role research has noted, proper access to the sick role requires a passive and compliant patient. Therefore, patients who are empowered and seeking their own solutions, especially solutions outside of the medical system, are not viewed as compliant and trusting and therefore may not be allowed to access the sick role. As a result, FMS patients appear to have few, if any, legitimate options for obtaining the rights and benefits provided by the sick role.

Therefore, the results of the current study illustrated the need for further research to explore the connections among leisure-based self-care, agency, and the sick role. Specifically, the paradox among these three concepts should be explored further in order to determine the positive and negative impacts of agency on the lives of people with illnesses. In particular, theoretical studies examining both successful and unsuccessful negotiations of the sick role, and

the role of agency in those negotiations, would help shed further light on the behavior of people with a variety of illnesses.

Ramifications of failure to fulfill the sick role. Few, if any, studies have explicitly examined the sick role as a societal script and also examined the implications for people who are unable to fulfill that script. This study was able to do both. In doing so, the results of this project shed light on the social, psychological, and tangible ramifications of participants' failures to adhere to the sick role, and they do so from a patient's perspective. In particular, the experiences of participants in this study illustrated that a failure to follow each part of the sick role may result in psychological distress as well as social stigma or isolation. For instance, the inability to access the diagnosis phase of the sick role may result in anxiety about one's health and the true cause of one's symptoms. Similarly the overall failure to receive the social support-related benefits of the sick role may result in real or perceived threats to disability insurance and other tangible benefits. As a result, future studies should include, for example, Goffman's ideas about stigma and social roles in order to better understand the complexity of the consequences for people who cannot adhere to the sick role script. The current study was only able to suggest these linkages, but the scope of this study did not allow for a full exploration of the role of stigma or social ramifications in an illness context.

The current study was also able to add nuance and context to existing leisure research concepts, particularly coping as self-care and leisure-based constraints. Specifically, participants' experiences indicated that coping is a vital part of living with a chronic illness like Fibromyalgia, and that the ability of leisure to provide spaces for joy and happiness are paramount. On the other hand, the experiences of participants in this study also indicated that people with chronic nonratified illnesses such as Fibromyalgia are likely to be severely

constrained in their ability to participate in the activities of daily life. While participants were able to negotiate some of these constraints through measures such as making choices or modifying activities or equipment, most if not all still experienced a severe limiting of their leisure repertoires. As a result, the experiences of participants in this study suggest that multiple facets of leisure behavior, from self-care to coping to constraints, play vital roles in the lives of people with Fibromyalgia Syndrome. Future research may find that these roles extend to other nonratified chronic illnesses such as Irritable Bowel Syndrome or Chronic Fatigue Syndrome and in doing so broaden our understanding of the potentially powerful roles of leisure in the lives of people with a variety of chronic conditions.

Recommendations for Action

The experiences of participants in this study also suggest a variety of practical actions that may be taken by healthcare and leisure providers alike. For instance, medical schools and residency programs should add a review of the sick role to their already mandated social science curriculum. Doing so would help raise doctor's awareness of the implicit scripts their patients may feel compelled to follow, and may also provide doctors with the tools to question and critically appraise their own personal scripts about the appropriate behavior of the ill. This may be particularly relevant in light of increasing movements towards patient agency and involvement in care as doctors will need to be even more aware of the scripts their patients rely on in order to develop their expectations for medical encounters.

Moreover, healthcare providers at all levels, but especially nurses and doctors, should work with leisure professionals to present chronically ill patients with the tools they may need to cope with their symptoms, negotiate constraints, and pursue some forms of self-care. As Robinson-Smith et al. (2000) suggested, healthcare workers, especially those involved in

rehabilitation programs, are in an ideal position to promote patients' self-efficacy and self-care behaviors. Similarly, Richardson and Ream (1997) asserted that, "through imparting knowledge, and assisting patients to develop relevant skills, nurses can teach self-care activities and augment patients' self-care agency" (pg. 36). However, the addition of leisure professionals such as rehabilitation therapists, programmers, and researchers is essential. As Coleman (1993) suggested, "an understanding of the links between leisure and health may help in the design of preventive health strategies and could be used to direct leisure service delivery" (p. 350).

Recreation Program Design. Participants in this study also made it clear that they would like leisure programs designed especially for people with Fibromyalgia or other chronic pain conditions. For instance several participants said that when they look at pamphlets for exercise classes, they cannot always tell if they should sign up because of the stigma associated with Fibromyalgia. Moreover they are often embarrassed to call and talk to the instructor about their particular limitations. Therefore, many participants said that they would like recreation facilities to advertise the specific classes that are suitable for people with chronic pain conditions such as arthritis or Fibromyalgia, and specifically several participants said that they would like to see promotional materials indicating "Fibro patients welcome" or "arthritis friendly." Similarly other participants said that they needed help modifying leisure and recreation activities so that they could safely participate. They referenced the types of programming provided for people with disabilities and wondered if the same sorts of modifications could be made for people with chronic pain conditions.

The experiences of participants in this study suggest that small modifications to program designs have the potential to make significant impacts in the lives of people with FMS. After all, for participants in this study, exercise and leisure activities played a large role in daily

Fibromyalgia management. As a result, leisure and recreation providers should take steps towards assisting Fibro patients in getting regular physical activity.

Finally, participants in this study stressed the need for additional biomedical research aimed at finding not only the cause of Fibromyalgia but also a medical cure. The vast majority of participants in this study were dissatisfied with current medical treatments and were either allergic to or experience serious side-effects from the medications that are currently on the market. As a result they would like to see more money spent on understanding Fibromyalgia and exploring alternative medical treatments.

The Intent and Limitations of this Study

The current study was designed to address the everyday lived experiences of people with Fibromyalgia Syndrome by providing a forum for collecting and analyzing their stories. However, as with all study designs, this design has inherent strengths and weaknesses. For instance, the results of this study are not, nor were they intended to be, generalizable to a larger population. As a result, I cannot speculate about the percentage of people whose experiences mirrored those of the participants in this study. Additionally, the study sample was a small convenience sample consisting almost exclusively of people who were diagnosed with Fibromyalgia by a physician and subsequently had access to some form of healthcare. Therefore, I am not able to speak to the experiences of low-income, minority, or medically ostracized Fibromyalgia patients. It may be that people experiencing FMS completely outside the medical system, either because of choice or necessity, have very different experiences than those working from within the system.

Therefore, while I was able to link various concepts in the literature with the everyday experiences of patients, I cannot claim that those assertions hold true for anyone outside of the

participants in this study. Instead, I would suggest that in order to really understand Fibromyalgia Syndrome, the sick role, and leisure-based self-care in a holistic manner, scholars should utilize the wide array of tools in their research toolbox. Although this particular study was well-suited for gathering rich and complex information about the daily lives of patients with Fibromyalgia Syndrome, this study alone cannot speak to those experiences with any final authority. As a result, the current study is should be best understood one of many necessary contributions to the larger effort of understanding the lived experiences of people with socially and psychologically complex chronic illnesses.

Conclusion

The experiences of participants in this study indicated that they had a strong desire to follow the steps outlined by the sick role despite their inability to do so successfully. Moreover, participants' narratives illustrated that they hoped to receive benefits normally reserved for those whose experiences are in line with the sick role, namely societal acceptance of their illness, a meaningful diagnosis, effective treatment, and an eventual recovery/return to normalcy. Therefore, participants often sought these benefits either exclusively through leisure-based self-care measures or by utilizing leisure-based self-care as a compliment to their medical treatments. As a result, the main theoretical contribution of this study was its ability to suggest that people with Fibromyalgia Syndrome may utilize leisure-based self-care as an alternative to the sick role. Moreover, in doing so, many participants in this study displayed a certain amount of agency. However, an examination of the literature indicates that agency in an illness context is potentially detrimental to a person's ability to fulfill the sick role. As such, there is a paradox relating agency, the sick role, and leisure-based self-care, and that paradox deserves further academic attention.

This study was also able to shed light on the social, psychological, and tangible consequences of participants' failures to adhere to the sick role. More importantly the current study, unlike previous research, examined these consequences from patients' perspectives of their everyday lives. These ramifications were often linked to leisure-based coping and leisure-based constraints, and as a result the narratives presented here were also able to add nuance and context to those concepts. In particular, participants' experiences indicated that coping through leisure is a vital part of living with Fibromyalgia, and in particular the ability of leisure to create happiness and fun was essential. On the other hand, the experiences of participants in this study also indicated that people with chronic nonratified illnesses such as Fibromyalgia are likely to be severely constrained in their ability to participate in the activities of daily life. These constraints encompassed interpersonal, intrapersonal and structural barriers. Moreover, while some participants were able to negotiate their constraints through measures such as making choices or modifying activities or equipment, most if not all people in this study nevertheless experienced a severe limiting of their leisure lives.

Finally, this project created a space for the voices of a medically marginalized group whose experiences have been understudied in leisure and health research. Indeed, when I asked study participants themselves about their desires for this project, many of them hoped that it would increase people's understanding of and compassion for people with FMS. Participants also mentioned more pragmatic goals such as providing exercise classes for people with Fibromyalgia or receiving help modifying existing recreation programs. As a result, this study was able to contribute to our understandings of Fibromyalgia, leisure, and the sick role both theoretically as well as on a practical level.

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Appendix A: Focus Group and Interview Guide

Introduction and purpose of study

Opening Question

1. To start, could you please tell me what a typical day with Fibromyalgia is like for you?

Transition Questions

2. When did you first begin experiencing symptoms of Fibromyalgia?
3. Did you know anything about Fibromyalgia before that time?

Main Questions - Set 1: Symptoms

1. Does anything particularly aggravate your symptoms?
2. Does anything help to relieve your symptoms?
3. When you experience symptoms, do you experience them as having unique causes (i.e. I overused my right arm yesterday so today the Fibro is particularly affecting that arm) or do you experience them as somewhat random manifestations of Fibro (i.e. the location of discomfort from day to day feels random)?

Main Questions - Set 2: Leisure

1. In your experience, does Fibromyalgia primarily impact your body, your mind or your spirit? (Or all?)
 - a. [Using your above response] what do you believe that means for providing appropriate quality of life experiences for people with Fibromyalgia?
 - b. What activities have you found that best address the mind, body and/or spirit impacts you face? (Note: these may be passive activities like Internet chatting or active activities like yoga)
4. Have you stopped doing things that you used to do since your symptoms began?
 - a. If so, why?
5. Have you started new activities since your symptoms began?
 - a. If so, why?
 - b. What about Internet-based activities?
 - c. What about stress-relieving activities?
6. Have you found that there are activities you find pleasure in even when your symptoms are present?
 - a. What about social activities?
 - b. What about relaxation activities like taking a hot shower or bath?

7. Could you foresee ways that your favorite activities could be modified so you could participate?
 - i. If yes, how?
 - ii. If not, why?

8. Could you please suggest some specific ways that gyms, recreation centers or parks and recreation departments could modify existing programs or facilities to help improve your quality of life? Some things to consider:
 - a. Water therapy?
 - i. If yes, specifically what water temperature helps?

 - b. What specific classes would you like to join?
 - i. How could those classes be modified?

 - c. Should advertising materials specifically invite people with “chronic pain conditions” to participate?
 - i. If yes, what should the ads say?
 - ii. If no, why?

Main Questions, Set 3: Focus on medical and leisure professionals

9. Have you had any interactions with medical professionals about your illness?
 - a. What have those interactions been like?

10. Have you had any interactions with people who provide alternative therapy? (i.e. acupuncturists or herbalists?)
 - a. What have those interactions been like?

11. Have you had any interactions with leisure professionals like yoga instructors, massage therapists or weight trainers?
 - a. What have those interactions been like?

Transition Questions

1. Are there things that you think are particularly important for people to know or understand about Fibromyalgia?
2. Do you have any thoughts about why FMS primarily affects women?
3. What do you hope comes out of your participation in this [focus group/interview] today?
4. What do you think is in your future in terms of Fibromyalgia?

Ending Questions

1. Of all the issues we've discussed today, which one is most important to you?
2. Is there anything we should have talked about but didn't?
3. Do you have any words of hope or encouragement for others with FMS who might read this study?