Predicting Subjective Well-Being in Women with Fibromyalgia: An Application of a Feminist, Biopsychosocial Framework of Chronic Illness and Disability

by

Rana Yaghmaian

A dissertation completed in partial fulfillment of
the requirements for the degree of

Doctor of Philosophy
(Rehabilitation Psychology)
UNIVERSITY OF WISCONSIN-MADISON
2016

Date of final oral examination: 05/12/2016

Dissertation Committee:

Susan Smedema, Assistant Professor, Rehabilitation Psychology & Special Education
Fong Chan, Professor, Rehabilitation Psychology & Special Education
David Rosenthal, Professor, Rehabilitation Psychology & Special Education
Brian Phillips, Assistant Professor, Rehabilitation Psychology & Special Education
William Hoyt, Professor, Counseling Psychology

DEDICATION

I dedicate this dissertation to my parents,
Margie and Abbas Yaghmaian, and
to my uncle, Johnny Fromm.

この論文を両親の
マーギとアバス ヤグマイアン、
そして叔父のジャーニー フロムにささげます。

عباس یغمائیان عباس و.
و مارجی پدرم و
مادر به تقدیم
فروم جانی عمویم

ACKNOWLEDGMENTS

This dissertation would not have been possible without the support and encouragement of many people. First, I would like to thank the members of my committee for their contributions in the completion of my dissertation: Dr. Susan Smedema, Dr. Fong Chan, Dr. Brian Phillips, Dr. David Rosenthal, and Dr. William Hoyt. You have each been instrumental to this process, and I am deeply grateful for the wisdom and time you have provided to ensure my success. Dr. Smedema, words fall short in expressing my gratitude for your unwavering support over these past three years. As my major advisor, you have been truly exceptional, and I could not have reached the heights that I have without your guidance, encouragement, and sense of humor. Dr. Chan, you have been a steadfast source of help, understanding, and inspiration. Thank you for always reminding me that life works out just as it should. Dr. Phillips, I have always felt supported by you in my commitments to social justice for women and other minorities with disabilities; thank you for always making me feel heard. Dr. Rosenthal, a very special thanks to you for your endeavors to help me through the recruitment process, as well as for being a respected mentor since I was a master's student. Dr. Hoyt, I am so grateful for your willingness to meet with me many times to provide your valuable suggestions and advice, as well as for sharing your boundless knowledge of methodology; this study would not be what it is without your help.

I would also like to extend a heartfelt thanks to two additional mentors, Dr. Norm Berven, and Dr. Eboneé Johnson-Milligan. Dr. Berven, thank you for being a part of this journey since I first set foot on the UW campus in 2008. I will always cherish your presence in my life. Eboneé, I am so glad to call you a mentor, colleague, and friend. I know that we have many years of collaboration ahead of us, and I am so excited to see what the future has in store. Also, to all of the wonderful friends I have made at UW, thank you for the hours of shared work and laughter. Especially to my dear friends Kristen Berg, Holly Aldrich, Michael Mensinga, and Michele Mahr, I am indebted to each of you for being a compassionate, empathetic ear and/or a hilarious respite from the arduous task of earning a PhD. To the wonderful, brilliant, and inspiring women who were are part of “Feminist Fridays”, I am so grateful to have found kindred spirits in you during my time here at UW; our State Street gatherings will always be a treasured part of my Madison memories.

I must also extend a special thanks to Fibromyalgia Awareness, FibroToday.com, and The New Fibromyalgia AWARE Magazine for their assistance with participant recruitment. Also, many thanks to the women who took the time to participate in this study. This dissertation would not have been possible without your willingness to share your stories through my survey.

Lastly, to my parents: to thank you in words is not enough. I have so much gratitude for the nearly 30 years of support, guidance, and love. This is for you.

TABLE OF CONTENTS

Chapter Five: Discussion

Appendices

LIST OF TABLES AND FIGURES

ABSTRACT

Fibromyalgia syndrome (FMS) is a complex disorder that has been subjected to much controversy due to its ambiguous nature, subjective manifestation, and often-unsuccessful treatment. Persons with this diagnosis, particularly women, experience a great deal of frustration, stress, and relational dissatisfaction in their daily lives. FMS is especially unique, as the intersectionality of the diagnosis extends beyond gender and illness alone; the highly stigmatized nature of FMS complicates the processes through which women with this diagnosis are able to achieve full inclusion in social and community life and overall well-being. The present study sought to employ a feminist, biopsychosocial framework of chronic illness and disability in predicting subjective well-being (SWB) in women with FMS. Furthermore, it aimed to determine the potential buffering effect of illness centrality on the relationship between FMS severity and life satisfaction. Lastly, the investigator aimed to measure participation in a way that weighted perceived functioning in life roles in accordance with their importance to the individual; thus, the Meaningful Role Functioning Questionnaire (MRFQ) was developed in conjunction with the present study. In the primary research model, socioenvironmental factors were represented by physician-patient working alliance and physician stigma, biological factors were represented by FMS severity, psychological factors were represented by illness centrality, participation was represented by meaningful role-functioning, and SWB was represented by positive affect, negative affect, and life satisfaction.

The study included 229 participants identifying as women who had FMS for one year or more. Structural equation modeling (SEM) was used to determine the joint influence of the biopsychosocial factors on SWB. Results indicated that the proposed model did not fit the sample data. Following model modifications, the respecified model indicated a strong model-to-data fit, with physician-patient working alliance, FMS severity, illness centrality, and meaningful role-functioning predicting 79% of the variance in SWB. Results of the moderation analysis indicated that illness centrality was not a significant moderator of the relationship between FMS severity and life satisfaction. Lastly, the MRFQ was found to be a reliable measure of role-functioning in this sample of women with FMS, with a test-retest reliability coefficient of .74. Furthermore, the MRFQ correlated significantly with other biopsychosocial constructs, including the variables in the primary research model, as well as social support, core self-evaluations, and chronic pain stigma. The findings in this study extend the current literature on the biopsychosocial factors that influence well-being in women with FMS, reinforcing the notion that SWB is more powerfully predicted by accounting for the joint influence of health condition, socioenvironmental, and psychological factors, as opposed to any of the single factors alone. This study further provides context for evaluating a biopsychosocial model through a feminist lens. Additional implications for rehabilitation research and practice are discussed.

CHAPTER ONE

Introduction

> *We need a theory of disability…. This theory should be feminist, because more than half of disabled people are women and approximately 16 percent of women are disabled (Fine & Asch, 1988), and because feminist thinkers have raised the most radical issues about cultural attitudes to the body (Wendell, 2006, p. 243).*

Health is an important aspect of any individual's life, particularly for a person living with a chronic illness or disability. Historically, health has been defined as the absence of disease (Eberst, 1984); however, health is beyond a purely biological experience (Engel, 1977). Social and personal systems serve as powerful forces in constructing definitions of "good health" and in affecting the lived experiences of individuals experiencing illness and disability.

The factors influencing the health and illness experience are widespread, and can range from modifiable to nonmodifiable elements of the health condition, the individual, and the environment. One relatively stable factor that plays a central role in how health, illness, and disability are experienced is gender. Gender can impact the ways in which the general public, medical professionals, and loved ones respond to an individual's health status, and yet, gendered health concerns have been historically neglected in both research and practice. In particular, a widespread commitment to women with chronic illness and disability has yet to be achieved within the fields of medicine, psychology, and rehabilitation. Until the last two decades, women's health was not of prime concern in the medical and academic research communities (Institute of Medicine [IOM], 2010). Historically, minorities with disabilities, including gender minorities, have been positioned under the umbrella of all persons with disabilities, neglecting to acknowledge the heterogeneity of experience amongst individuals carrying multiple minority statuses. Thus, empirical investigation of the medical and psychosocial determinants of health and well-being in women with chronic conditions is still in its infancy. Furthermore, there have been fewer advances in research surrounding the experiences of individuals with chronic, non-fatal conditions that disproportionately affect women, which limits empirical and clinical knowledge of the factors relevant to quality of life (QOL) and longevity in persons who carry these diagnoses (IOM, 2010).

Fibromyalgia syndrome (FMS) is one of the most elusive and widely-debated illnesses affecting women. FMS is a disorder of undetermined etiology characterized by diffuse musculoskeletal pain, distinct tender points, fatigue, sleep disturbance, headaches and migraines, irritable bowel syndrome, and cognitive difficulties (Smith, Harris, & Clauw, 2011). FMS has historically been a controversial disorder, and its recognition as a legitimate category of physical illness has been widely debated; thus, persons with FMS often receive delayed and ineffective care, which can significantly impact QOL (Smith, 2009). While anyone can be diagnosed with FMS, it is primarily a women's disorder. Women are 7 to 10 times more likely than men to be diagnosed with the disorder (Howard et al., 2010). While the reasons for these sex disparities are still under investigation, the numbers are staggering enough that FMS can be considered a significant women's health issue. Accordingly, FMS explicitly fall under the Institute on Medicine's (IOM) description of "women's health", which refers to any health condition that is specific to women, is more common or manifests with greater severity in women, has specific causes or disease manifestations in women, has different treatments and outcomes in women, and has high morbidity or mortality rates in women (IOM, 2010).

A diagnosis of FMS can drastically affect well-being, both generally and in ways that are gender-specific. The physical symptoms of the illness are only one facet of the FMS experience;

for women with FMS, social definitions of illness, attitudes toward medically intangible diagnoses, gender-role expectations, and psychological factors play dominant and interactive roles in QOL outcomes. While the academic literature has more recently attended to the psychosocial impact of FMS, the gendered experiences of women with FMS have been understudied. Continued research is necessary in order to identify the factors related to QOL in women with FMS, and identify the relationships between these factors and how they interact to affect QOL.

Assumptions and Theoretical Framework

A feminist, biopsychosocial framework of disability. Within the past several decades, feminist disability scholars have advocated for the advancement of inclusive theory and research, particularly that which addresses the unique experience of women with disabilities. The feminist theoretical perspective, which attends to power imbalances based on gender and disability, is particularly relevant for women with FMS. Women representing this illness category lie at an intersectionally unique space of societal invalidation as women, invalidation as women with disabilities, and in particular, invalidation as women with stigmatized disability identities. An important facet of feminist disability theory is that, while its primary focus is on the sociocultural environment, feminist disability theorists also acknowledge that there are instances in which biology does and should count (Fine & Asch, 1988); thus, the biological implications of having a chronic illness or disability are not discounted or trivialized. The present research applies an integrative, biopsychosocial framework of disability informed by feminist disability theory, with biological factors seeking to understand how an individual's physical and emotional functioning influence well-being, environmental factors seeking to understand how an individual's sociocultural context influences well-being, and psychological factors seeking to understand how an individual's internal processes related to her self worth and self-concept influence well-being.

The International Classification of Functioning, Disability, and Health. While the driving theoretical framework for this study is feminist disability theory, any strong theory needs a model through which to guide empirically-driven methods and practically-relevant results. The advancement of theory-driven research is essential to better understanding the underlying mechanisms of human behavior and outcomes, and models help to link theory with the practical concerns of rehabilitation counseling service-delivery (Bellini & Rumrill, 2002). Model-driven research and practice has been established by leading rehabilitation scholars as the standard by which all rehabilitation professionals should base their work. This reflects a long-espoused value in rehabilitation, which is to provide individuals with disabilities with the most effective services by grounding clinical practice in evidence-based interventions (Chan, Chronister, & Cardoso, 2009a; Chan, Tarvydas, Blalock, Strauser, & Atkins, 2009b; Dunn & Elliot, 2008). Model-driven research promotes a common language between all stakeholders invested in improving the lives of persons with disabilities, including health and rehabilitation professionals, researchers, policy makers, and individuals with disabilities and their families (Chan et al., 2009b; Peterson, 2005).

The current "gold standard" of biopsychosocial disability models is the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). The ICF is consistent with the strengths-based values long advocated by rehabilitation professionals and disability advocates, as it places equal emphasis on environmental, psychological, and health condition factors. The ICF builds upon its predecessors by taking an enablement approach toward disability that synthesizes the medical, functional, and social models of health and illness (Chan, Gelman, Ditchman, Kim, & Chiu, 2009c). The integration of these perspectives allows for application across a wide range of health-related disciplines. The ICF model comprises two basic parts: (1) functioning and disability and (2) contextual factors. These parts are then subdivided into four broad components: (1) *body functions and structures*, which represent physiological and anatomical abilities and impairments; (2) *activities and participation*, which represent the execution of basic life tasks and engagement in a variety of life situations; (3) *environmental factors*, or components of the physical, social, or attitudinal world that impact the disability experience; and (4) *personal factors*, which can include a wide range of nonmodifiable (e.g. race/ethnicity, age, gender) and modifiable (e.g. coping style, self-efficacy) factors that influence the disability experience (WHO, 2001). Figure 1 presents a graphical depiction of the ICF model as originally developed by WHO.

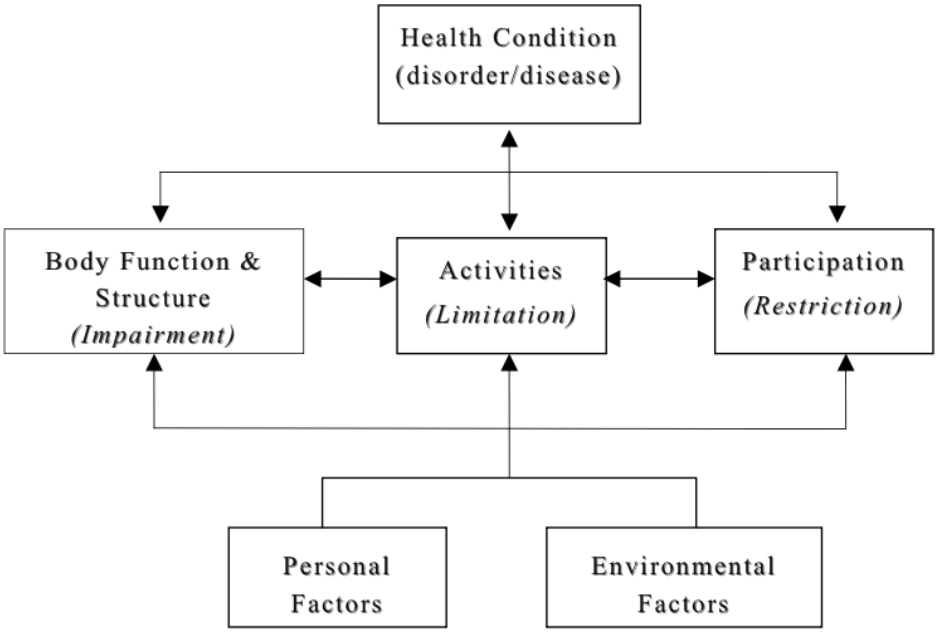


Figure 1.1 The ICF Model as Conceptualized by WHO (2001)

A critical evolution of the ICF model is reflected in Chan and colleagues' (2009c) addition of QOL as the main outcome variable influenced by all other components in the model.

Figure 2 represents a graphical depiction of the factorial relationships between all components of the ICF model, including QOL, as conceptualized by Chan and colleagues (2009c).

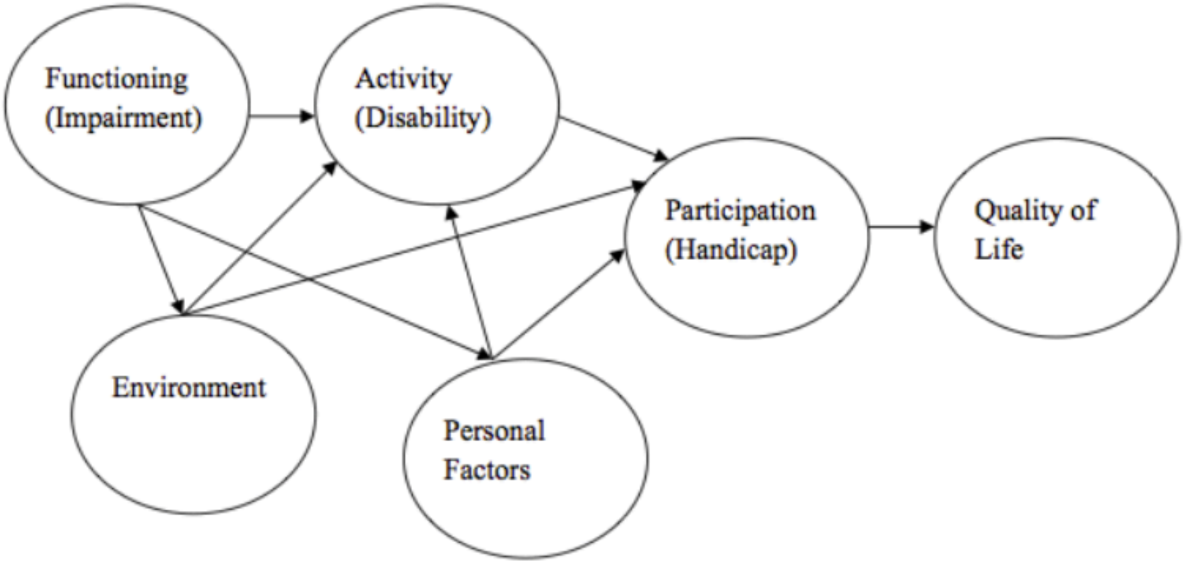


Figure 1.2 The ICF Model as Conceptualized by Chan et al. (2009c).

This study will use the ICF framework as a guide through which to integrate feminist theory and a biopsychosocial framework. One of the central advantages of the ICF model is its flexibility in interpretation, as it allows for the variables of focus to be specific to the health condition. Flexibility is an important facet of this study, as no known scholars have explicitly developed an empirically-testable model representing the key feminist and biopsychosocial concerns of persons with FMS or related illnesses.

Statement of Purpose

The primary purpose of this study is to contribute to the knowledge base regarding women with FMS, using a feminist, biopsychosocial framework of chronic illness. More specifically, the study aims to expand the biopsychosocial understanding of FMS using a unique theoretical framework that represent the concerns of women with FMS through a feminist lens. At present, no known quantitative studies in rehabilitation or otherwise have examined the biopsychosocial predictors of well-being in women with FMS through a feminist framework. Furthermore, no known studies in rehabilitation have interpreted the biopsychosocial model through a feminist lens. This study will not only contribute to the knowledge base for this particular population of women, but will also enhance the theory- and model-driven frameworks through which rehabilitation professionals conceptualize the lived experiences of women with chronic illness and disability.

The biopsychosocial conception of disability and feminist disability theory are congruent in that they both emphasize the social and attitudinal environments as highly impactful components of the disability experience. The present study seeks to represent variables and relationships that are informed by feminist disability theory and the FMS literature. The variables explicitly related to the environment are central to the conceptualization of this model as a feminist framework; the literature consistently points to empowering or disempowering encounters with healthcare professionals, family members, social support systems, and the general public as fundamental elements of psychological functioning, physical functioning, and overall well-being in this population of women. The following represent the biological, psychological, and socioenvironmental factors included in the central research model:

1. Health condition factors are represented by *FMS severity*;

2. Environmental factors are represented by *physician patient working alliance* and *physician stigma*;
3. Psychological factors are represented by *illness centrality*;
4. Participation is represented by *meaningful role-functioning*; and
5. SWB is represented by *positive affect*, *negative affect*, and *life satisfaction*.

In order to inform future research surrounding meaningful role-functioning as a measure of participation, as well as to aid in scale validation, several additional biopsychosocial constructs known to be associated with participation and well-being were included in the present study. These constructs include: *core self-evaluations*, *perceived social support*, *chronic pain stigma*, and *participation in society*. Furthermore, to aid in the interpretation of the quantitative results, several open-ended prompts were included in the survey. These prompts asked participants to describe the ways in which FMS affects their functioning in meaningful life roles, the ways in which they perceived being an individual with FMS influences how others treat them, and the ways in which they perceived being a woman influenced how others treat them.

Research Questions

Using structural equation modeling, hierarchical regression, and Pearson product-moment correlation analyses, the following research questions were examined.

Research Question 1. Using structural equation modeling, does the SWB model based on a feminist, biopsychosocial framework of disability fit the data collected among women with fibromyalgia?

Research Question 2. In the proposed structural equation model, do the following specified paths indicate one factor significantly predicting the other?

a. Medical environment directly predicting FMS severity

b. Medical environment directly predicting SWB

c. FMS severity directly predicting meaningful role-functioning

d. FMS severity directly predicting illness centrality

e. Illness centrality directly predicting meaningful role-functioning

f. Meaningful role-functioning directly predicting SWB

Research Question 3. Does illness centrality moderate the relationship between FMS severity and life satisfaction?

Research Question 4. Which constructs included in this study are significant external correlates of meaningful role-functioning, as measured by the Meaningful Role Functioning Questionnaire?

CHAPTER 2

Literature Review

Disability in general puts an individual at risk for economic deprivation, denial of communicative self-representation, and denial of access to a preferred way of life (Mpofu, Beck, & Weinrach, 2004). The intersection of gender and disability can result in a double-jeopardy minority-status that creates differentially oppressive circumstances for gender minorities with disabilities (Purdie-Vaughns & Eibach, 2008). According to Ferri & Gregg (1998), women with disabilities are subject to "dual silence and oppression" (p. 429), an experience that is underscored by the lack of disability perspective in feminist studies and is also evident in the research surrounding the educational, vocational, economic, and psychosocial experiences of women with disabilities (Erevelles & Minear, 2010; Shaw, Chan, & McMahon, 2012). The wide gaps in social movements, theories, and research have substantially limited the development of empirically based interventions for women with disabilities seeking support through medical and mental health professionals.

Historically, persons with disabilities possessing multiple minority identities have been subject to the pitfalls of single-identity politics (Blackwell-Stratton, Breslin, Mayerson, & Baily, 1988). For example, there has been a lack of a disability perspective in feminist theory and practice. Likewise, the disability rights movement failed to investigate how gender and race impact disability and vice versa. This partitioning of objectives and ideologies resulted in an ableist women's movement and a sexist disability movement. Similarly, there is a substantial body of literature emphasizing the interaction of race, gender, and class, but a lack of literature that acknowledges disability as significant in the study of intersecting social identities (Shaw et al., 2010). Asch and Fine (1988) suggest that one reason for this exclusion could be that disability “eclipses” other dimensions of social experience. Thus, it is wrongly assumed that disability is always the most salient and exclusive status in a person’s life. However, women with disabilities reside at the intersection of gender *and* disability and are often invalidated by societal perceptions of who or what satisfies biological “normality” and who maintains power on the basis of gender (Mason, 2004). Thus, disability and gender are mutually significant in everyday life.

Feminist Disability Theory

While first-wave feminism was primarily concerned with gender-based inequality, feminist perspectives have evolved from a purely male/female focus to an approach that critiques the socio-structural conditions of power and oppression on the basis on multiple intersections of identity. Correspondingly, the feminist perspective on disability attends to contextual issues and power differentials as they relate to the intersections of disability, gender, race, ethnicity, age, socioeconomic status, and so on. Some scholars have suggested that feminist frameworks pay the greatest justice to the experiences of women with health concerns, as they account for exposure to social and environmental inequalities on the basis of both gender and illness, while also acknowledging the interaction of these identities with other facets of identity such as race, class, and sexual orientation (Andrist, 1997; Banks, 2010; Brown-Travis & Compton, 2001; Einstein & Shildrick, 2009; Ferri & Gregg, 1998; Reverby, 2002; Scoville, 2005; Wendell, 1996).

Like other social justice theories, feminist disability theory is driven by the prospect of social change. A central goal of the feminist disability movement is to transform non-inclusive political, social, and environmental systems of oppression, while simultaneously acknowledging the biological complications that arise from having a disability. The integration of feminist theory and disability theory indeed makes practical sense; disability and femaleness have long been associated with one another in historical Western thought, and for centuries, the female body and mind, similar to the bodies and minds of persons with disabilities, have been characterized as incomplete, dependent, and powerless (Garland-Thomson, 2011). Much like feminist scholars have regarded gender as a social construction, disability scholars who subscribe to the social model of disability view the notion of disability as fabricated by the structural conditions that define the “ideal” body (Hahn, 1993).

Feminist Theory and FMS

The feminist perspective is particularly relevant for women with FMS. In terms of chronic illnesses, FMS carries with it a relatively amount of ambiguity, which threatens social, cultural, and medical definitions of illness. According to White and colleagues (2001), the key feminist issues affecting women with FMS are deeply rooted in the values of Western medicine and the contemporary medical model of illness and disability. These sources of psychological and physical distress are based on the scientific method, which values objectivity and generalizability; this approach is particularly problematic for women with FMS, given the lack of scientific evidence for symptoms, the heterogeneity of symptom presentation, and the fact that the pain and fatigue they experience are “subjective realities” (p. 54). The authors further state, “because subjective knowledge is personal, not universalizable, it is not considered acceptable evidence for ‘hard’ science” (p. 54).

Despite efforts in rehabilitation to shift disability paradigms to reflect a biopsychosocial conceptualization of the disability experience, one that encapsulates factors beyond the functional and medical aspects of disability alone, the values of the medical model continue to prevail in the general public and in medical settings (Albrecht, 1992; Smart & Smart, 2006). Within the medical model, disability is viewed as an individual experience that is unaffected by social and attitudinal influences. Not surprisingly, the feminist approach staunchly rejects the medical model of illness and disability, which problematizes the individual, rather than critiquing the social environment for its lack of inclusivity and regard for persons with disabilities. Wendell (2006) argues that through the contemporary medical model, doctors in particular are driven to fix and control the individual, playing the role of the hero. She further contends that individuals with uncontrollable and chronic conditions threaten medical professionals' socialized need to play this role. Pain, Wendell states, is particularly enigmatic, and persons experiencing pain are unjustly blamed for their symptoms. She argues,

> The pernicious myth that it is possible to avoid almost all pain by controlling the body gives the fear of pain greater power than it should have and blames the victims of unavoidable pain. The fear of pain is also expressed or displaced as a fear of people in pain, which often isolates those with painful disabilities (p. 250).

While the functional and social models of disability improved upon the problem-focused nature of the medical model, it is generally accepted that integrative, biopsychosocial models of disability are the most preferred in conceptualizing the nature of health conditions. The highly regarded biopsychosocial conception of the disability experience acknowledges both the biological underpinnings of disability and the social constructions that confound the disability experience. Biological variables indeed represent important factors in the chronic illness and disability experience; however, feminist disability scholars have argued that the instances in which biology independently predicts outcomes are extremely rare, and that improving sociocultural attitudes toward women with disabilities would significantly weaken the relationship between biological factors and well-being (Fine & Asch, 1988).

A feminist, biopsychosocial model of well-being. Importantly, to predict QOL in women with FMS using the social environment alone would represent an incomplete model of chronic illness and disability. Fine and Asch (1988) contend that both the disability rights and women's movements "share the indisputable fact that in some situations biology *does* and *should* count" (p. 26). Furthermore, countless studies have demonstrated that personal, psychological factors play an influential role in how illness and disability are experienced, particularly for individuals with chronic pain conditions. Accordingly, this study will employ a biopsychosocial framework informed by feminist theory in order to comprehensively capture the experiences of women with FMS.

A major draw in conceptualizing well-being in women with FMS through a biopsychosocial approach is that this notion of health, illness, and disability is congruent with the integrative, person-environment approach advocated by both rehabilitation and feminist scholars (e.g. Wright, 1960; 1972; 1983; Wendell, 2006). A biopsychosocial perspective provides a context for defining health-related conditions through a framework that is inclusive of all possible factors affecting functioning and disability. Through the biopsychosocial approach, professionals are encouraged not only to focus interventions toward the individual, but also toward the physical, social, and attitudinal environments. By modeling disability through a holistic framework, the biopsychosocial conceptualization of illness presents as an ideal structure to more comprehensively conceptualize the illness experience based on its various biological, social, and psychological dimensions.

Factors Affecting Quality of Life in Women with FMS

Quality of life is a multidimensional construct defined by both objective and subjective factors (Bishop & Feist-Price, 2001; Fabian, 1991; Roessler, 1990). Chapin, Miller, Ferrin, Chan, and Rubin (2004) broadly define QOL as consisting of the following elements: freedom of action, sense of purpose, work achievement, family or social/recreational life, self-preservation of esteem and integrity, and physical and material well-being. Historically, QOL in persons with chronic illness and disability was conceptualized as a unidimensional, functionally-based construct (Bishop, Chapin, & Miller, 2008). Objective indicators of QOL such as pain levels, functional disability, and employment status are indeed influential factors contributing to psychological well-being. However, it has been argued that focusing exclusively on objective indicators of QOL provides an insufficient and misleading picture of what it means to live a fulfilling and satisfying life (Chapin et al., 2004). Accordingly, subjective dimensions of QOL such as life satisfaction, affect, and aspects of the self-concept have gained considerable traction in research aiming to identify the predictors of QOL in persons with disabilities (Bishop & Feist-Price, 2001; Fabian, 1991; Roessler, 1990; Smedema, Catalano, & Ebener, 2010). Accordingly, in the present study, QOL will be conceptualized as SWB (SWB), which is characterized by both cognitive and affective domains of QOL. Diener, Eunkook, and Oishi (1997) conceptualized SWB as a three-component model that includes a cognitive judgment about satisfaction with life, high levels of positive affect (the extent to which an individual feels excited, strong, active, and inspired), and low levels of negative affect (the extent to which an individual feels distressed, hostile, irritable, and nervous).

Studies and reviews aiming to synthesize the issues affecting well-being in persons with FMS often capture a myriad of biological, psychological, and socio-environmental factors that ultimately influence QOL, indicating that no single factor alone predicts QOL in persons with FMS. Much of the FMS literature suggests that environmental factors such as diagnostic ambiguity due to poor and ineffective medical care, relationships with medical personnel, and stigma have a significant impact on health-related QOL and SWB in women with this diagnosis (White, Lemkau, & Clasen, 2001). Furthermore, stress and restricted lifestyles associated with the health condition, personal factors (e.g. illness self-concept, self-esteem, self-efficacy), and participation in major life roles (e.g. family member, friend, worker) have also been found to be empirically predictive of well-being in persons with chronic pain conditions similar to FMS (Christler, 2001; Sutanto et al., 2013). The following sections will detail the factors associated with QOL in women with FMS.

Health condition factors. FMS is a rheumatic disorder characterized by widespread musculoskeletal pain, often co-existing with other somatic and psychological symptoms that can significantly affect QOL (Campos & Vázquez, 2012). Symptoms of FMS are wide-ranging and generally chronic, although there are periods of remission in which symptoms are either non-existent or very mild. More often than periods of remission are periods of time called “flare” in which symptoms are very active, causing high intensity pain and grief. It is also common that the discomfort associated with FMS (e.g. stiffness, pain, and cognitive strain) is most severe in the morning, requiring additional time and effort to begin the day (White et al., 2001).

Physical and cognitive symptoms. The physical and cognitive factors associated with FMS are interactive and widespread, and many of these factors have bidirectional relationships. The most common symptom of FMS is severe, flu-like pain, which can present as aching, throbbing, shooting, stabbing, or intense burning pain and usually occurs throughout the entire body, particularly in the neck, mid and lower back, chest, arms, and legs (Mannerkorpi & Ekdahl, 1997). From a psychosocial perspective, chronic pain dynamically interacts with other biological factors, psychological factors, and social/contextual factors, all of which can influence or be influenced by pain levels. While the precise cause of FMS pain has not been determined, there is evidence to suggest that individuals with FMS experience abnormalities in central pain processing, which produce heightened responses to painful stimuli (*hyperalgesia*) and painful responses to nonpainful stimuli (*allodynia*; Clauw, 2009). These responses indicate that FMS-related pain is more likely to be associated with abnormalities in sensory processing, as opposed to an abnormality in the region of the body where pain is experienced. One study assessing after-sensations of heat in FMS and control patients found that 83% of participants with FMS reported painful after-sensations at 15 seconds compared to 37% of healthy controls. At two minutes after heat stimulation, 55% of participants with FMS reported pain, as compared to 5% of healthy controls (Staud, Vierck, Cannon, Mauderli, and Price, 2001). Another study found that at the same level of thermal stimulation, participants with FMS perceived pain as 49% and 52% more intense than healthy controls and participants with low-back pain, respectively (Julien, Goffaux, Arsenault, & Marchand, 2005). Giesecke and colleagues (2004) reported that after receiving equal amounts of pressure at a neutral site on the body, individuals with chronic low back pain and FMS experienced significantly more pain and showed more extensive patterns of neuronal activation in pain-related areas in the brain as compared to healthy controls.

Tender points are also common in persons with FMS. Tender points are particular areas on the body that, when pressure is exerted upon them, cause pain. There are 18 tender points located on nine bilateral muscle locations including the front neck, front chest, back of the neck, back shoulders, shoulder blades, elbows, rear end, rear hips, and knees (Marcus, 2008). Other common symptoms in persons with FMS include fatigue, or a constant feeling of exhaustion, problems with sleep functioning, irritable bowel syndrome (IBS), neurologic disturbances (e.g. numbness, tingling, burning feelings in extremities), dizziness, sinus problems, and rashes (Alloway, 1999; Marcus, 2008). Also acknowledged, but less studied, has been the dyscognition associated with FMS (Ambrose, Gracely, & Glass, 2012). Informally known as “fibro fog”, these symptoms can present as difficulties with complex cognitive processes such as working, semantic, and episodic memory; executive functioning; and concentration and attention (Ambrose et al., 2012).

Psychiatric symptoms. Co-existing psychiatric disorders are also common in persons with FMS. Research has demonstrated that individuals with FMS have more psychological symptoms than individuals with other types of pain (Gormsen, Rosenberg, Bach, & Jensen, 2010) and that somewhere between 30% and 45% of persons with FMS experience symptoms of depression, anxiety, and heightened stress (Kurtze, Gundersen, & Sveback, 1998). These psychological symptoms are strongly associated with symptom presentation and severity, including higher levels of perceived pain and increased risk for more severe syndrome presentation (Aparicio et al., 2013).

The causal relationship between FMS symptoms and psychiatric disorders has been widely debated. While there is little evidence to suggest that FMS is a purely psychological disorder (Aparicio et al., 2013), some individuals with FMS may have a predisposition to certain psychiatric concerns. For instance, evidence suggests that individuals with FMS report higher levels of negative affect, which is linked to more maladaptive coping (Zautra, Hamilton, & Burke, 1999), while more positive affect is associated with higher levels of resiliency in the face of stress, an increased pain threshold, less pain, and generally more favorable scores on perceived health (Cogan, Cogan, Waltz, & McCue, 1987; Stalling, 1992; Zautra et al., 1999; Zautra & Manne, 1992).

Psychological Factors. Psychological factors refer to unique aspects of the individual’s intrapsychic processes that interact with the illness and disability experience. The psychological factors influencing outcomes in women with FMS are wide-ranging; the primary research model in this study will use a variable reflecting the individual's appraisal of her illness as either central or peripheral to the core self. This variable is referred to as *illness centrality,* though it should be noted that the concept was originally called *illness self-concept*. The change in variable name was intended to aid in the interpretation of illness centrality relative to other factors, such that other variables could be understood in relation to the degree to which the illness dominates the core self.

Illness Self-Concept. The onset of chronic illness and disability triggers a dynamic process of physical and psychological adjustment, a process that often results in a changed perception of self (Morea, Friend, & Bennet, 2008; Smedema et al., 2010). Regarding women with chronic illness specifically, Zuchowski (2011) states,

> Women's lives start to shift when they become ill and begin to lose the objects that anchored their previously well selves: paid work, financial independence, hobbies, full participation in a social life. Instead these are replaced with doctors' visits, support groups, negotiating health care structures, and attempts to secure disability benefits. The ill individual's life becomes reformed in relation to the activities of living with a chronic illness (p. 178).

This shifting of lifestyles and emphasis placed on certain life areas may influence the ways in which women with FMS view themselves in relation to their illness. Recently, Morea and colleagues introduced the theory and construct of illness self-concept (ISC), which describes the extent to which chronic illness dominates the individual's self-concept. Drawing from life space theory (Asch, 1952; Chiaramonte & Friend, 2006; Lewin, 1951), the authors characterized ISC by the degree to which the illness is central or peripheral to the core self. The authors describe an illness occupying central regions of life space as a driving force affecting many other regions of life space. An illness inhabiting peripheral regions of life space, rather, is dependent on the individual’s core definition of self and depends on these core life space regions for definition and interpretation. Ideally, the illness occupies peripheral regions of life space; in these cases, the illness is seen as a constructive challenge, as opposed to a burden. ISC theory further acknowledges the interactive nature of illness and varying contextual and situational factors, including a supportive or unsupportive social environment, illness severity, and illness progression, which makes ISC as a well-suited construct to examine in a biopsychosocial framework.

To further delineate ISC and its state as either central or peripheral to the core self, Morea and colleagues (2008) identified three constructs that describe the position of the illness in the life space: (a) directionality, which references the causal relationship between the illness and the self, or whether or not the self is a driving force for the illness or the illness is a driving force for the self; the former of the two represents an individual whose illness occupies central life space, and needs, actions, goals, and relationships are interpreted through the illness; (b) pervasiveness, which references how much of the life space is occupied by the illness; if the illness is central, then many parts of the self will be affected by the illness. Conversely, if the illness is peripheral, then other parts of the self will be protected from the illness; and (c) illness self-consciousness, or the extent to which individuals are preoccupied by their illness; individuals who rarely think about their illness have low illness self-consciousness.

Morea and colleagues (2008) developed the Illness Self Concept Scale (ISCS) and targeted a sample of persons with FMS in order to predict illness adjustment in a population of individuals whose illnesses are likely to encroach upon their central regions of life space, thus becoming a part of and guiding evaluations of the whole self. A number of factors contribute to the identification of this population as high risk for developing a centralized ISC. The uncertainty of the illness, vulnerability to stigma, varying levels of severity (e.g. times of flare vs. times of symptoms remission), and generally pervasive effects accompanying this diagnosis all add to the possibility that persons with FMS will integrate the illness into their central core selves (Morea et al., 2008). The authors found that ISC predicted unique variance in health-related outcomes (e.g. health status, illness intrusiveness, life satisfaction, and depression) over and above other widely-acknowledged predictors of adjustment (e.g. self-esteem, optimism). In fact, self-esteem and optimism were not significant predictors of illness-related adjustment after controlling for ISC.

Socio-environmental factors. Socioenvironmental variables refer to aspects of the elements of the physical, social, and attitudinal environments that serve as either barriers or facilitators to support the independence and inclusion of individuals with disabilities (Oliver, 1990; Schneidert et al., 2003). WHO (2001) classifies environmental factors into domains representing both the individual level (e.g. support and relationships, products and technology in an individual's immediate environment) and societal levels (e.g. social systems, services, policies, and attitudes) of the environment. Consistent with feminist disability theory, the present study focuses primarily on the medical environment, with *physician-patient working alliance* and *physician stigma* as the primary socioenvironmental variables included in the research model.

Physician-patient working alliance. For decades, researchers in counseling and psychology have studied the unique impact of the collaborative relationship between client and therapist on therapy outcomes, commonly referred to as the working alliance. The working alliance represents a cooperative and trusting relationship, one that takes into consideration both the therapist's and the client's capacities to form an agreed-upon plan regarding goals, tasks, and outcomes (Horvath & Symonds, 1991). Bordin (1979) described the working alliance as encompassing three critical components: (a) agreement upon treatment goals (b) agreement upon tasks to achieve treatment goals; and (b) an emotional bond characterized by trust and fondness between the client and therapist. Hundreds of studies have been conducted to better understand the influence of the working alliance in the treatment of various psychological problems; taking into account the findings across these studies, it can be concluded that the working alliance is the single most reliable predictor of psychotherapy outcomes (Wampold, 2000).

With a growing emphasis in the field of medicine on patient-centered care (Elwyn et al., 2014; Epstein & Street, 2011; Reynolds, 2009), the concept of the working alliance has been extended to relationships between patients and their medical providers (Fuertes et al., 2007). It has been postulated that the working alliance is as important of a factor in relationships with medical providers, particularly in predicting both objective and subjective health outcomes (Fuertes et al., 2007). Fuertes and colleagues (2007), recognizing gaps in the medical literature concerning an explicitly articulated conceptualization of the physician-patient working alliance, as well as a dearth of instruments to accurately capture this relationship, developed the Physician-Patient Working Alliance Inventory (PPWA) to better account for the cognitive and emotional dimensions of the working alliance concept in medical settings. Two studies in particular have demonstrated that the physician-patient working alliance predicts adherence to treatment and satisfaction with healthcare services (Fuertes, Boylan, & Fontanella, 2008; Fuertes et al., 2007). Fuertes et al. (2008) found moderate to strong relationships between working alliance ratings and physician empathy, multicultural competence, perceived utility of treatment, and treatment adherence self-efficacy.

At present, no known studies exist examining the physician-patient working alliance in persons with FMS. Given the factors reviewed related to both gender and stigma in healthcare settings, women with FMS indeed appear to be a fitting population through which to study such a construct. In comparison with other chronic illnesses, FMS is notoriously difficult to diagnose, particularly in the early stages. Individuals with FMS characteristically present with a host of symptoms that often fail to meet the criteria for a clinical diagnosis, and time between initial presentation of symptoms and receiving a diagnosis can be prolonged by the obscurity of the illness (White at al., 2001). Illness ambiguity can provoke a number of psychosocial concerns related to diagnostic closure, prognostic uncertainty and dismissal on the part of physicians due to vague symptomatology (Christler, 2001; Sutanto et al., 2013; White et al., 2001). For individuals with highly ambiguous conditions, physician-patient working alliance may be a crucial predictor of outcomes.

Physician stigma. Stigma is broadly defined as an attribute that is “deeply discrediting” (Goffman, 1963, p. 3) that links a person to undesirable characteristics or stereotypes (Jones et al., 1984), and ultimately has the potential to result in some form of discrimination (Link & Phelan, 1999). Regarding FMS, White and colleagues (2001) state, “Perhaps the most problematic aspect of this illness is the discrepancy between the patient’s experience of pain and suffering and the absence of both objective physical findings and a biomedical explanation” (p. 52). This incongruity between symptoms and visibility can create situations in which women with FMS feel stigmatized and discredited by others. Lilleaas (1995, as cited in Werner, Isaksen, & Lakterud, 2003) found that women with FMS experienced their diagnosis as highly stigmatized and invalidated, both in their personal and professional surroundings. Physician stigma in particular is a widespread concern for individuals with FMS, and has the potential to result in inadequate and inappropriate care. Åsbring and Närvänen (2002) found that women with FMS and CFS perceived that medical professionals often attributed symptoms to a psychological cause prior to any sufficient medical testing. Furthermore, clinicians challenged their trustworthiness after diagnostic testing proved inadequate in identifying concrete pathology, which for some women, led to a mental health referral. These investigators also found that women with FMS felt stigmatized and devalued based on this illness being considered primarily a women's condition.

The above findings are unsurprising given women's gendered experiences in healthcare settings. Christler (2001) suggested that women experiencing illness ambiguity may undergo gender-specific challenges when working with medical personnel. For decades, studies have demonstrated that in comparison with their male counterparts, women seeking healthcare are perceived as more emotionally unstable and burdensome, and women are more likely to be diagnosed with a psychosomatic disorder when experiencing physical symptoms (Armitage, Schneiderman, & Bass, 1979; Bernstein & Kane, 1981). Women who attempt assertiveness and challenge physicians and other clinical staff may be personified as difficult, excessively demanding, and emotionally unstable, thus further delaying accurate diagnosis and the ability to effectively self-manage symptoms (Christler, 2001). Vague and inaccurate diagnoses may give rise to feelings of existential uncertainty, anxiety, stress, and powerlessness (Joachim & Acorn, 2003; Miller, 2000; Nettleton, 2006); in persons with chronic illness, higher levels of illness ambiguity has consistently been found to be associated with poorer physical and psychological outcomes and lower QOL (Baily et al., 2009; Hoth et al., 2013).

Participation and meaningful role-functioning. In rehabilitation, participation has been conceptualized as one of the most important outcome variables in biopsychosocial conceptions of disability. Participation is generally defined as full social inclusion in the community, though the operationalization of the construct has been widely debated. In a report detailing the proceedings of the 2010 International Symposium on Measurement of Participation in Rehabilitation Research, Heinemann et al. (2010) stated that defining participation is as complex and subjective as defining the "good life." In an effort to gain an "insider perspective" from people with disabilities in defining and characterizing participation, Hammel and colleagues (2007) conducted a qualitative study, sampling 60 individuals with various disabilities. Results indicated that six major domains of participation values emerged: Meaningful Engagement; Personal and Societal Responsibilities; Having an Impact on Supporting Others; Social Connection, Inclusion, and Membership; Access and Opportunity; and Choice and Control. Participants expressed desiring the freedom to define and pursue participation on their own terms rather than measuring whether they met predetermined societal norms or standards. Furthermore, the participants viewed participation as a dynamic process that involved the negotiation and balancing of needs and values across individual, social and societal levels. This study seeks to account for a subjective dimension of participation by defining participation in terms of meaningful role-functioning, or an individual's perceived importance of select life roles and perceived functioning in life roles.

Life roles and role-identity have long been a topic of interest in the fields of counseling and psychology, specifically with regard to the ways in which personal, developmental, and situational factors impact an individual's participation in life roles at any given period in time. In 1980, Super developed and conceptualized the life career rainbow, which is a component of his life span, life space approach to career development. The life career rainbow was developed as a means to help individuals understand and express the socio-environmental, situational, and personal determinants of past, present, and future life-role salience and participation. In this theory, Super identified nine primary life roles: child, student, worker, partner, parent, citizen, homemaker, leisurite, and pensioner. Super (1980, 1990) suggested that the importance one places on certain life roles is dependent upon a number of internal and external factors that change and evolve throughout the life span. Regarding the prominence of specific life roles in an individual's life, Super, Savickas, and Super (1996) stated that the "social elements that constitute a life are arranged in a pattern of core and peripheral roles and this arrangement, or life structure, forms the basic configuration of a person's life" (p. 128); it has been suggested that when individuals have a high level of self-awareness concerning their life roles and life-role salience, they are more likely to be prepared for and better adapt to the internal and external forces affecting changes in life-role participation (1980).

The literature in social psychology suggests that life roles are indeed central factors in the formation of a self-conception, and that the possession of one or more role identities can promote psychological health (Thoits, 1992). However, stressful life circumstances have the potential to impede upon meaningful role-fulfillment. For women with FMS, role-fulfillment may be interrupted by pain, fatigue, sleep problems, dyscognition, anxiety, depression, and so on (Arnold et al., 2008). Scholars in social psychology have argued that stressful life events and circumstances are only psychologically distressing when the stress interrupts life domains or roles that the individual values, identifies with, or finds meaning in (Burke, 1991; Thoits, 1991). Prior literature in rehabilitation has also placed emphasis on the concept of domain importance (Frisch, 1999). Bishop et al. (2008), in reviewing the assessment of QOL, stated, "a more accurate and meaningful assessment of QOL results from weighing satisfaction in those specific life domains that are more highly valued or important to the individual (p. 48). Thus, fulfillment of life roles becomes problematic when the individual’s illness presentation clashes with the individual’s subjectively meaningful roles.

Gender-role expectations may further complicate the social participation of women with FMS. From a very young age, girls are socialized in ways that prepares them for distinct roles associated with relationally-focused behaviors and functions (Bronstein, 2001). This socialization communicates to girls and women that their identities, self-conceptions, and responsibilities are inextricably intertwined with their abilities to nurture, fix, mend, and maintain relationships, reducing the power and control they have over other important areas of their lives (Cancian, 1987, Miller, 1976; Scoville, 2005). While experiencing general and gendered illness concerns, women with FMS are also expected to fulfill traditional gender roles such as the caregiver or the nurturer, while simultaneously fulfilling other roles such as worker, student, and community citizen (Scoville, 2005).

The phenomenon of psychological and interpersonal stress resulting from attempts to fulfill gendered expectations has been termed “superwoman syndrome”. As cited in Scoville (2005), Shaevitz (1984) states, “Superwoman is a perfect mother, the model wife, the best housekeeper, the most available daughter, the most effective worker, the most helpful friend. She is wonderful at juggling home and career with a constant smile and an even disposition. She is everything to everyone” (p. 1). The superwoman notion is particularly salient for women with FMS; it has been suggested that women with FMS may have a personality-based proclivity toward perfectionism (Sansone, Levengood, & Sellbom, 2004), and studies have demonstrated that the onset of FMS may correspond with elevated levels of perfectionism and an overactive lifestyle (Van Houdenhove, 2003; Van Houdenhove, Neerinckx, Onghena, Lysens, Vertommen, 2001). Molnar, Flett, Sadava, and Colautti (2012) found that while overall levels of perfectionism did not appear to be elevated in women with FMS, those women with FMS who were particularly high in self-reported perfectionism also reported lower health functioning. Moreover, with gender role expectations pressuring women to fulfill social roles without failure or imperfection, the intersection of gender and chronic illness may give rise to feelings of inadequacy and lowered self-efficacy, thus adversely affecting well-being.

While the literature surrounding social and community participation in persons with disabilities indicates that participation is a highly subjective construct, there are few known instruments designed to measure participation in a way that captures the individualistic nature of the concept. There are existing measures that account for the importance of life domains (e.g. Cummins, 1997; Ferrans & Powers, 1985; Frisch, Cornell, Villanueva, & Retzlaff, 1992); however, these measures were developed as measures of QOL, not participation. For instance, the Quality of Life Inventory (Frisch et al., 1992) measures satisfaction in a range of life areas, including finances, work, self-esteem, and creativity; likewise, the Quality of Life Index (Ferrans & Powers, 1985) and the Comprehensive Quality of Life Scale (Cummins, 1997) measure domain importance and satisfaction not only in life roles, but also in other areas of life, such as financial independence, the amount of worries in life the respondent has, the achievement of personal goals, safety, health, and happiness, making the measures better geared toward evaluating overall QOL. The present study aimed to measure participation in a similar manner, though as a predictor rather than an indicator of QOL. To achieve this goal, the investigator developed a new self-report scale called the Meaningful Role-Functioning Questionnaire (MRFQ), which measures the following sub-constructs: (a) *perceived role-importance*, or the extent to which an individual views a particular life role as significant, meaningful, and valuable; and (b) *perceived role-fulfillment*, or a subjective evaluation of one's current level functioning in select life roles. While not specifically a career development measurement tool, the life roles represented in the MRFQ were, in part, informed by the life roles included in Super's (1980) Life Career Rainbow. Additionally, a number of external variables were chosen for the purposes of construct validation, including core self-evaluations, chronic pain stigma, and social support. Since life role participation is said to be influenced by personal/psychological and socioenvironmental factors, it was predicted that meaningful role-functioning would be significantly associated with these particular predictors of participation and well-being.

Variables used in MRFQ Construct Validation

Core self-evaluations. Core self-evaluations (CSE) is a relatively new, higher-order personality construct that has recently gained attention in the rehabilitation literature. Judge, Van Vianen, & De Pater (2004) defined CSE as "the fundamental evaluations that people make about themselves and their functioning in their environment" (p.326). CSE is characterized by four lower-order personality traits: (a) self-esteem, which references an individual's overall evaluation of her self-worth, (b) generalized self-efficacy, which represents a subjective evaluation of how well one can perform across a broad range of situations; (c) locus of control, which references the degree to which an individual perceives outcomes to be based on personal characteristics, as opposed to the external environment; and (d) emotional stability, which is the opposite of the personality trait neuroticism, and refers to an individual's propensity to feel calm and secure. According to Judge et al. (2004), ''Individuals with positive core self-evaluations appraise themselves in a consistently positive manner across situations; such individuals see themselves as capable, worthy, and in control of their lives'' (pp. 328–329).

To date, CSE has been studied primarily in fields outside of rehabilitation, though preliminary research suggests that CSE is a valuable construct to explore in relation to persons with disabilities. In the general population, CSE has been found to be predictive of happiness, life satisfaction, and overall physical and psychological health (Piccolo, Judge, Takahashi, Watanabe, & Locke, 2005; Tsaousis, Nikolaou, Serdaris, and Judge, 2007). Tsaousis et al. (2007) found that CSE explains a significant amount of variance in both physical and psychological health functioning; the same study found that CSE significantly moderates the relationship between SWB and physical health, indicating that persons with higher CSE demonstrated a stronger positive relationship between physical health functioning and SWB. High CSE has been found to be associated with fewer perceived stressors, lower levels of strain, and the use of more problem-focused coping strategies (Kammeyer-Mueller, Judge, & Scott, 2009). In addition, research findings suggest that CSE is related to both positive and negative affect (Judge, Thoreson, Pucik, & Welbourne, 1999). In rehabilitation counseling research, CSE has been reported to directly or indirectly predict a number of positive psychological outcomes important to persons with disabilities, including hope, perceived health, autonomy, social support, participation in work and education, and life satisfaction (Smedema, Chan, & Phillips, 2014; Smedema, Pfaller, Yaghmaian, Weaver, Cardoso, & Chan, 2015; Smedema & Tansey, 2014; Yaghmaian & Smedema, under review).

While no known studies exist referencing the effects of CSE on FMS-related outcomes, the four domain-level traits associated with CSE have been empirically-supported predictors of outcomes in persons with FMS. For instance, one study found that women with FMS reported lower self-efficacy scores than healthy women. The results showed that pain intensity, sleep quality, anxiety, and depression were each correlated in the expected directions with scores on self-efficacy (Miró, Martínez, Sánchez, Prados, & Medina , 2011). Self-esteem is also a concern for individuals with chronic pain disorders. In a meta-analytic review, Burke, Mathias, and

Denson (2015) demonstrated that individuals with chronic pain experienced difficulties in a wide range of psychological domains, including self-esteem. Unsurprisingly, research has also demonstrated that women with chronic pain experience a decreased sense of personal control over their life circumstances, particularly given that such conditions are often dependent upon others to acknowledge the legitimacy of an FMS diagnosis (Skuladottir & Halldorsdottir, 2008). Schuster, McCormack, Riddell, and Toplak (2009) reported that in comparison with healthy controls, women with FMS reported higher levels of external locus of control, which was significantly associated with higher ratings of anxiety and depressed mood. Regarding emotional stability, in testing the effects of a multidisciplinary treatment program for persons with FMS and other painful and nonpainful conditions, Torres and colleagues (2013) found that women with FMS can be clustered into subgroups, one of which included women who displayed high levels of neuroticism (low emotional stability) and low levels of extraversion; this subgroup reported worse pretreatment clinical state, more psychosocial problems, and higher levels of anxiety and depressed mood.

Stigma. In a qualitative study, Dennis, Larkin, and Derbyshire (2013) found that relational uncertainty, or concerns regarding relationships with family members and colleagues, was a major concern for individuals with FMS. Family members ranged from understanding, to understanding with still-high expectations, to stigmatizing and shame-inducing. The same study found that the participants experienced challenges in managing disability disclosure and coworker relationships in the work setting. In a study of women with FMS and CFS, Åsbring and Närvänen (2002) found that participants with these diagnoses experienced stigma in multiple forms. The women in this study reported that others often doubted the authenticity of their symptoms, which caused others to question their individual characters. The participants attributed these suspicions regarding the veracity of symptoms to the invisibility of the illness.

Social support. Social support is a broad, multifaceted construct that represents any process through which social connections and relationships promote and facilitate health and well-being (Chronister, Johnson, & Lin, 2009; Chronister, Johnson, & Berven, 2006; Cohen, Gottlieb, & Underwood, 2000). The importance of social support in rehabilitation has been substantiated by the proliferation of support groups and social services for people and families coping with chronic illness and disability, across many institutional settings (Cohen, Gottlieb & Underwood, 2000). Social support has been identified as a variable that can reduce the impact of exposure to adverse psychological events, stressors, and life situations (Folkman & Moskowitz, 2004; Martz, Bodner, & Livneh, 2010; Ptacek & Pierce, 2003), and research has found that it is an important factor in the prevention of and susceptibility to illness, disease, and disability (Pierce, Sarason, & Sarason, 1996).

Social support is especially important for individuals with rheumatic disorders such as FMS. Loneliness and perceived social isolation are highly prevalent in persons with rheumatic disorders (Laidmäe, Leppik, Tulva, & Hääl, 2009; Rokach, Lechcier-Kimel, & Safarov, 2006), and research has demonstrated that persons with FMS experience significantly greater levels of loneliness, even compared to persons with other types of rheumatic disorders (Kool & Geenan, 2012). In a study examining the unique effects of illness invalidation and social support on health outcomes in persons with rheumatic disorders, Kool, van Middendorp, Lumley, Bijlsma, and Geenen (2012) found that social support was positively associated with scores on mental health. Similarly, another study reported that lower scores on perceived social support predicted higher levels of psychological distress (van Koulil, van Lankfeld, Kraaimaat, van Riel, & Evers, 2010).

There is also evidence to suggest that social support may contribute to reductions in subjective pain. Under experimental conditions, Montoya, Larbig, Braun, Preissl, and Birbaumer (2004) found that when participants with FMS were in the presence of their significant other as opposed to alone, there were significant reductions in pain sensitivity and subjective pain ratings; furthermore, brain activity upon elbow stimulation significantly reduced when these individuals were in the presence of a significant other.

Based on a review of the literature, it is clear that FMS should be explored through a biopsychosocial lens. Through a feminist framework, this study aimed to understand the interactive relationships between biological, psychological, and socioenvironmental variables and their influence on meaningful role-functioning and SWB. The following chapter will detail the present study in terms of research design, sampling and study procedures, participant characteristics, information about the selected instruments, and an overview of statistical methods.

CHAPTER 3

Methods

A primarily quantitative, cross-sectional, descriptive design was used to measure the hypothesized relationships in this study, employing structural equation modeling (SEM) to determine the relationships between latent biopsychosocial variables. In addition, a hierarchical regression analysis was used to conduct a secondary moderator analysis. To aid in the interpretation of quantitative results, several open-ended questions were also included in the survey.

SEM requires a fairly large sample size in order to reach an acceptable level of statistical power and to achieve an adequate level of precision for model estimates. A number of researchers have provided guidelines regarding what constitutes a sufficient sample size to conduct an SEM analysis. Quintana and Maxwell (1999) suggested that researchers should aim to recruit five to ten participants per estimated parameter, while Weston, Gore, Chan, and Catalano (2008) recommended conducting SEM analyses using at least 200 participants. In order to account for individuals who took the survey but did not meet inclusion criteria or provided incomplete data, the investigator aimed to recruit a minimum of 220 adult women with FMS.

Sampling and Procedures

The researcher completed the required Human Subjects Protection Training for the University of Wisconsin-Madison Institutional Review Board (IRB) and obtained study approval from the IRB (see Appendix A). Following IRB approval, the researcher contacted several fibromyalgia organizations via their respective social media accounts with invitations to participate in research collaboration. Participants were ultimately recruited through the Fibromyalgia Awareness Facebook page and their related website (FibroToday.com), as well as the Facebook page of The New Fibromyalgia AWARE magazine. Each organization agreed to post the study announcement on their main Facebook page, and the study announcement was also posted on FibroToday.com (see Appendix B for the study announcement). To be eligible for inclusion in this study, participants were required to meet the following criteria: (a) between 18 and 65 years of age, (b) had a diagnosis of fibromyalgia for one year or more.

Data were collected via an online survey platform (Qualtrics), and participants were provided a survey link through the study announcement. Via the informed consent (Appendix C), participants were informed of the voluntary nature of the study, their rights as a research participant, and the potential risks and benefits of participation. Participants were provided with the email address and telephone number of the principal investigator and student investigator, as well as the contact information for the UW Madison Educational and Behavioral Sciences IRB. Participants were asked to read and endorse the informed consent form before they proceeded with the survey. To protect confidentiality, the personal information of the participants was not connected to their survey responses. Participants were informed of the opportunity to obtain a $15 Target gift card via email by signing up and providing contact information upon completing the survey. The first 200 participants to take the original survey received a $15 gift card.

For analysis purposes, one of the survey questionnaires required a retest after four weeks (28 days). The survey system was programmed such that participants that opted-in for the retest would receive an email prompting them to take the retest questionnaire exactly 28 days after they took the original survey. Participants were informed of the opportunity to obtain an additional $10 gift card via email for taking part in the questionnaire retest; the first 30 participants to complete the retest survey received a $10 gift card. Again, participants' contact information was not connected to their survey responses.

Participants

A total of 351 individuals attempted the online survey. After checking for inclusion criteria and item completion rates 229 (65.2%) participants were retained. Methods for determining item completion rates and multivariate outliers are described in the data analysis section.

Sample Characteristics

Descriptive data and demographic frequencies for the participants are presented in Table 3.1. The mean age of participants was 46.7 (*SD*=10.7). The mean age of FMS onset was 32.2 (*SD*=10.8), while the mean age at diagnosis was 38.0 (*SD*=9.8). 210 (92.1%) of the participants identified as White, followed by 8 (3.5%) identifying as Hispanic/Latino, 4 (1.8%) identifying as Asian American/Pacific Islander, 3 (1.3%) identifying as African American, 2 identifying as Native American (0.9%), and 1 (0.4%) identifying as other. In terms of educational attainment, 42 (18.4%) of the participants had a master's degree or higher, 43 (18.9%) had a bachelor's degree, 47 (20.6%) had a associates degree or vocational certificate, 54 (23.7%) had some post-secondary education with no degree, 38 (16.7%) had a high school diploma or equivalent, 3 (1.3%) had secondary education with no high school diploma, and 1 (0.4%) had an elementary education (grades 1-8). In terms of marital status, 26 (11.4%) of the participants were single, 135 (59.2%) were married, 38 (16.7%) were divorced, 7 (3.1%) were widowed, 8 (3.5%) were separated, and 14 (6.1%) were unmarried, but cohabitating. Regarding employment status, 71 (31.1%) of the participants had full-time employment, 24 (10.5%) had part-time employment, 35 (15.4%) were retired, 6 (2.6%) were students, 4 (1.8%) were volunteers, 8 (3.5%) were unemployed and actively looking for a job, 77 (33.8%) were unemployed and not looking for a job, and 3 (1.3%) were unemployed but receiving vocational services. 34 (14.9%) of the participants had received vocational rehabilitation services at some point. Regarding health insurance status, 14 (6.1%) had no health insurance, 36 (15.8%) had Medicare, 25 (11.0%) had Medicaid, 7 (3.1%) had public insurance from some other source, 55 (24.1%) had insurance through their own employers, 65 (28.5%) had insurance through a spouse of family member’s employer, 14 (6.2%) had private insurance, and 12 (5.3%) identified as having some other form of health insurance not listed. Regarding social security beneficiary status, 9 (4.0%) participants reported having Supplemental Security Income (SSI), 50 (22.1%) reported having Social Security Disability Income (SSDI), 140 (61.9%) reported having none, and 15 (6.6%) reported having some other form of social security benefits not listed.

Table 3.1 Participant Demographic and Disability Characteristics (*n*=229)

Demographic Covariate	**Category**	***n* (%)**	***M* (*SD*)**
Age			46.70 (10.73)
Age at FMS Onset			32.21 (10.79)
Age at FMS Diagnosis			38.04 (9.81)
Race	Caucasian	210 (92.1%)	
	African American	3 (1.3%)	
	Hispanic/Latino	8 (3.5%)	
	Asian American or Pacific Islander	4 (1.8%)	
	Native American	2 (0.9%)	
	Other	1 (0.4%)	
Marital Status	Single	26 (11.4%)	
	Married	135 (59.2%)	
	Divorced	38 (16.7%)	
	Widowed	7 (3.1%)	
	Separated	8 (3.5%)	
	Cohabitating	14 (6.1%)	
Education Level	Elementary	1 (0.4%)	
	Secondary, no high school diploma	3 (1.3%)	
	High school graduate or equivalency	38 (16.7%)	
	Post-secondary, no degree	54 (23.7%)	
	Associates degree or	47 (20.6%)	
	vocational/technical certificate	43(18.9%)	
	Bachelor’s degree	42 (18.4%)	
	Master’s degree or higher		

Employment Status	Full-time (more than 30 hours per week)	71 (31.1%)
	Part-time (less than 30 hours per week)	24 (10.5%)
	Retired	35 (15.4%)
	Student	6 (2.6%)
	Volunteer	4 (1.8%)
	Unemployed but actively looking for a job	8 (3.5%)
	Unemployed but not looking for a job	77 (33.8%)
	Unemployed but receiving vocational services	3 (1.3%)
Health Insurance Status	No insurance	14 (6.1%)
	Medicare	36 (15.8%)
	Medicaid	25 (11.0%)
	Public insurance from other source	7 (3.1%)
	Insurance through own employer	55 (24.1%)
	Insurance through spouse or family member's employer	65 (28.5%)
	Private insurance through self or family member	14 (6.1%)
	Other	12 (5.3%)
SSA Beneficiary Status	Supplemental Security Income (SSI)	9 (3.9%)
	Social Security Disability Income (SSDI)	51 (22.4%)
	None	141 (61.8%)
	Other	15 (6.6%)
	Unanswered (missing data)	12 (5.3%)
Received vocational rehabilitation services	Yes	34 (14.9%)
	No	193 (84.6%)
	Unanswered (missing data)	1 (0.4%)
Other health conditions	No other health conditions	11 (4.8%)
	Physical disability	30 (13.2%)
	Mental illness	62 (27.2%)
	Arthritis	83 (36.4%)
	Chronic fatigue syndrome	75 (32.9%)
	Irritable bowel syndrome	105 (46.1%)
	Raynaud's syndrome	28 (12.3%)
	Temporomandibular joint disorder (TMJ)	53 (23.2%)

Instrumentation

Demographic questionnaire. Participant demographic and FMS-specific information was requested in part to assess the generalizability of the sample. The demographic questionnaire consisted of information related to age, race/ethnicity, marital status, educational attainment level, employment status, history of vocational rehabilitation services. FMS-specific information included age at FMS onset, age at FMS diagnosis, health insurance status, social security beneficiary status, and any other secondary health conditions (e.g. physical disability, mental illness, arthritis, chronic fatigue syndrome, irritable bowel syndrome, Raynaud's syndrome, temporomandibular joint disorder).

FMS severity. FMS severity was measured using the *Revised Fibromyalgia Impact Questionnaire* (FIQR; Bennett et al., 2009), which is a revised version of the original Fibromyalgia Impact Questionnaire developed by Burckhardt, Clarke, & Bennett (1991). The FIQR comprises 21 items, which are all rated on an 11-point, 0 to 10 numeric rating scale, with 10 indicating greater difficulty with tasks, more negative impact of FMS symptoms, and great symptom severity over the last 7 days. The FIQR is divided into three domains: function (e.g. brushing or combing hair, walking continuously for 20 minutes, lifting and carrying a full bag of groceries), overall impact (e.g. "Fibromyalgia prevented me from accomplishing goals for the week"), and symptoms (e.g."Please rate the quality of your sleep"). Scores range from 0 to 90 for the function subscale, 0 to 20 for the overall impact subscale, and 0 to 100 for the symptoms subscale. The total FIQR score is determined by dividing the function score by 3, leaving the overall impact score as is, dividing the symptoms score by two, and summing the scores of the three modified domain scores. The maximum total score is 100. Bennett et al. (2009) reported that in a sample of persons with FMS, rheumatoid arthritis, systemic lupus erythematosus, major depressive disorder, and healthy controls, the FIQR demonstrated strong correlations with comparable domains in the SF-36, and that the three FIQR domain scores predicted the eight SF-36 subscale scores. The authors reported an internal consistency reliability coefficient

(Cronbach’s alpha) of .95. The Cronbach’s alpha coefficient for the FIQR in the present study was .94.

Illness centrality. The *Illness Self Concept Scale* (ISCS; Morea et al., 2008) was used to measure illness centrality in this study. The scale intends to measure the extent to which illness is central or peripheral to the core self. The ISCS represents the three sub-constructs believed to comprise ISC (directionality, pervasiveness, and illness self-consciousness). Sample items to measure these sub-constructs include: “My illness is at the center of who I am.”(directionality); “I do not allow my illness to affect too many parts of my life.” (pervasiveness); and “I am preoccupied with my illness.” (illness self-consciousness). Thirteen items represent directionality, seven reflect pervasiveness, and three represent illness self-consciousness. Items are worded to reflect illness as central (e.g. “I feel consumed by my illness”) or illness as peripheral (e.g. “I see myself as a healthy person in spite of my illness”). Participants are asked to rate each statement on a 6-point Likert-type scale (1 = “strongly agree”, 6 = “strongly disagree”). Items are worded to reflect illness as peripheral are reverse scored to obtain an overall ISC score. In this study, items were reverse scored so that higher scores represented greater centrality of the illness to the participant’s self-concept. The authors reported an internal consistency reliability coefficient (Cronbach’s alpha) of .94. In the present study, the Cronbach’s alpha coefficient for the ISCS was .93.

Stigma. Physician stigma and chronic pain stigma were measured using the *Chronic Pain Stigma Scale* (CPSS). The CPSS was developed by Reed (2005) to measure perceived stigma toward chronic pain. The CPSS is a 30-item instrument designed to measure perceptions of stigma from multiple sources (general public, family, physicians) and across multiple dimensions of chronic pain (estrangement, attribution to psychological cause, malingering, bias against opioid analgesics, and general negative attitudes). Principal components factor analysis revealed a three-factor solution consistent with the three subscales (public, family, physicians). Participants respond on a 6-point Likert-type scale (1 = “Strongly Agree”, 6 = “Strongly Disagree”). Sample items include “People think less of someone who is unable to work because of chronic pain” (general public subscale); “Doctors think that people with chronic pain exaggerate their pain” (physician subscale); and “My family thinks that chronic pain is more of a mental or emotional problem than a physical problem” (family subscale). In a sample of 150 adults with moderate to severe chronic pain due to low back pain or osteoarthritis, the author found an excellent internal consistency reliability estimate (Cronbach’s alpha) of .91. The scale was also found to have a moderate, positive correlation with depression as measured by the Beck Depression Inventory-Second Edition, and a moderate, negative relationship with quality of life as measured by the Medical Outcomes Study Short Form-36 Mental Component Summary. The Cronbach’s alpha coefficient for the CPSS in the present study was .90.

Physician-patient working alliance. The *Physician-Patient Working Alliance Inventory* (PPWA) was used to measure working alliance between participants and their medical providers. Fuertes and colleagues (2007) developed the PPWA as a measure of the cognitive and emotional dimensions of the physician-patient relationship, or the working alliance. The measure is an adapted version of a working alliance scale used in psychotherapy research by Tracey and Kokotavic (1989). The PPWA is 12-item scale that measures dimensions of the working alliance, including agreement on tasks, agreement on goals, and the emotional bond. Items are rated on a 7-point Likert-type scale (1 = “Strongly Disagree”, 7 = “Strongly Agree”). Sample items include: “I believe that my doctor trusts me”, and “My doctor and I agree about the things I need to do to improve my health”. The PPWA was validated in a sample of 118 men and women with

HIV/AIDS, hypertension, diabetes, asthma, and cancer. Fuertes and colleagues (2006) reported internal consistency reliability estimates (Cronbach's alphas) of 0.93 for the overall scale, and 0.82, 0.72, and 0.89 for the tasks, goals, and bond subscales, respectively. A principal components analysis yielded a one-factor solution, indicating that the PPWA is a general measure of the physician-patient working alliance. In addition, the authors found that the scale was moderately to strongly correlated with measures of self-efficacy, adherence to treatment, beliefs about the utility of treatment, and satisfaction with health services. In the present study, the Cronbach's alpha coefficients for the physician, family, and general public subscales were .85, .90, and .77, respectively. The Chronbach's alpha coefficient for the overall scale was .92.

Meaningful role-functioning. The *Meaningful Role-Functioning Questionnaire* (MRFQ) was used to measure meaningful role-functioning in the present study. The MRFQ is a new, 20-item scale developed in conjunction with this study. The MRFQ is a self-report questionnaire that aims to have participants subjectively evaluate life-role functioning across several domains. The scale includes the following subconstructs: (a) *perceived role-importance*, or the extent to which an individual views a particular life role as significant, meaningful, and valuable; and (b) *perceived role-fulfillment*, or an individual's evaluation of their current level of functioning in select life roles. Respondents are asked to rate the level of importance of select life roles (e.g. "Being a parent", "Being a friend", "Having a job") on a 6-point Likert-type scale (0 = "I do not identify with this role", 5 = "Very important"). They are then asked to rate how well they believe they currently fulfill these roles on a 6-point Likert-type scale (0 = "I do not identify with this role", 5 = "Very well"). Scoring the MRFQ entails the following steps: (1) Add together each of the *role-importance item scores* to yield a *total role-importance score* (scores will range from 0 to 50); (2) Divide each *role importance item score* by the *total role-importance* *score*. This will yield *relative role-importance item scores*, the sum of which will add up to exactly 1. (3) Multiply the *relative importance score* by the *perceived role-fulfillment score*, yielding a role-functioning score for each item. (4) Sum each of the *role-functioning item scores* to yield a *total role-functioning score*. Total role-functioning scores range from 0 to 5, with higher scores indicating higher levels of role-functioning.

The statistical reliability of the MRFQ was assessed by obtaining a 28-day (4-week) test-retest reliability coefficient, which was computed via a Pearson product-moment correlation analysis. The 4-week test-retest reliability coefficient for the MRFQ was .74. For construct validation purposes, external correlates of the MRFQ were explored using Pearson product-moment correlation analysis.

Positive and negative affect. The *Positive and Negative Affect Schedule* (PANAS; Watson, Clark, & Tellegen 1988) was used to measure the affective components of SWB in the present study. The PANAS includes 10 positive (e.g. enthusiastic, proud, excited) and 10 negative (e.g. ashamed, nervous, afraid) emotion adjectives. Participants are asked to indicate the degree to which they experience these adjectives over the past week. Scores range from 10 to 50 for each scale, with higher scores representing higher levels of positive affect for the positive affect (PA) scale, and lower scores representing lower levels of negative affect for the negative affect (NA) scale. The authors reported internal consistency reliability coefficients (Cronbach’s alphas) for the PA and NA scales of .88 and .85, respectively. The PANAS was also found to be correlated in the expected directions with other measures of psychological well-being and distress, including depression and anxiety. In the present study, the Cronbach’s alpha coefficients for both the positive affect and the negative affect scales were .91.

Life Satisfaction. The *Satisfaction with Life Scale* (SWLS; Diener, Emmons, Larsen, & Griffin, 1985) was used to measure a subjective component of QOL in this study. The SWLS is a unidimensional measure of life satisfaction, consisting of five items (e.g. "I am satisfied with my life"). Respondents rate items on a 7-point Likert-type scale (1="strongly disagree", to 7= "strongly agree"). Scores range from 5-35, with higher scores indicating greater levels of life satisfaction. Diener and colleagues (1985) found that the SWLS was correlated with other important measures of well-being, including the Rosenberg Self-Esteem Scale and the Affect Balance Scale. The authors reported a two-month test–retest reliability coefficient of .82, as well as an internal consistency reliability coefficient (Cronbach's alpha) of .87 in a sample of 176 undergraduates from the University of Illinois. In the present study, the Cronbach's alpha coefficient for the SWLS was .85.

Core self-evaluations. The *Core Self-Evaluations Scale* (CSES; Judge, Erez, Bono, and Thoresen, 2003) was used in this study to directly measure core self-evaluations. The CSES contains 12 items, which are rated on a 5-point Likert-type scale (1= "strongly disagree", 5= "strongly agree"). For 6 of the 12 items, higher scores indicate higher levels of CSE (e.g. "When I try, I generally succeed"), and for the remaining reverse-scored items, lower scores indicate higher levels of CSE (e.g. "I am filled with doubts about my competence"). The CSES is consistent with CSE theory, as demonstrated in a one-factor measurement structure (Judge et al., 2003). Internal consistency reliability estimates (Cronbach's alpha) ranged from .81 to .87, and the one-month test-retest reliability was found to be .81 (Judge et al., 2003). In the present study, the Cronbach's alpha coefficient for the CSES was .86.

Social Support. In this study, social support was measured with the *Multidimensional Scale of Perceived Social Support* (MSPSS). Zimet, Dahlme, Zimet, and Farley (1988) developed the MSPSS to measure the respondent's perception of social support from three domains of social support: family, friends, and significant other. These domains represent the three subscales in the MSPSS. The overall scale is composed of 12 items (e.g. "My family really tries to help me"; "My friends really try to help me"; "There is a special person who is around when I am in need"). Items are rated on a 7-point type Likert-type scale (1= "Very Strongly Disagree", 7 = "Very Strongly Agree"), and subscale scores are computed by calculating the mean of the raw scores for all items in the subscale. The total score represents the mean of the scores obtained on the three subscales, with higher means indicating higher levels of perceived social support. The internal consistency reliability estimates (Cronbach's alphas) of the full and individual subscales range from .84 to .92 for the full scale, .81 to.90 for the family subscale, .90 to .94 for the friends subscale, and from .83 to.98 for the significant other subscale. The Cronbach's alpha coefficient of the MSPSS in the present study was .92 for the full scale.

World Health Organization Disability Assessment Schedule 2.0. The 8-item participation in society subscale of the *World Health Organization Disability Assessment Schedule (WHODAS) 2.0* 36-item scale was used as a well-validated measure of participation against which to compare the MRFQ. Participants are asked to indicate the level of difficulty they have experienced with particular life areas (e.g. "How much of a problem did your family have because of your health problems?") over the past 30 days on a five-point Likert scale (1 = "none", 5 = "extreme or cannot do"). Prior research has demonstrated that the WHODAS 2.0 participation subscale possesses strong psychometric properties. In terms of validity, the participation subscale was found to have moderate to strong correlations with other widely-used measures of functioning and quality of life (Üstün, Kostanjsek, Chatterji, & Rehm, 2010). Prior research also evaluated the reliability of the scale, demonstrating that the WHODAS 2.0

participation in society subscale had a test-retest reliability coefficient of .95 and a Cronbach's alpha coefficient of .95 (Üstün et al., 2010). The Cronbach's alpha coefficient of the participation in society subscale in the present study was .86.

Open-Ended Prompts

To aid in the interpretation of quantitative results, this study included four open-ended prompts/questions. The first prompt, "Please list any other important, significant, and/or meaningful life roles that were not included in the previous questionnaire", was included in relation to the MRFQ, with the purpose of identifying other common life roles not included in the original form of the questionnaire. The second prompt, "In the space below, describe the ways in which your fibromyalgia affects your ability (if at all) to successfully fulfill the life roles and/or life areas that are important to you" was included in order to garner a more full picture of how FMS may or may not interfere with meaningful life roles. The third and fourth prompts were included to supplement the scope-limited quantitative questionnaires in capturing aspects of feminist disability theory. These prompts stated: "In the space below, please describe how you feel being a woman affects the way people (including the general public, family members, and medical professionals) treat you. If you do not feel being a woman affects the way people treat you, please indicate that in the space below", and "In the space below, please describe how you feel being a person with fibromyalgia affects the way people (including the general public, family members, and medical professionals) treat you. If you do not feel being a person with fibromyalgia affects the way people treat you, please indicate that in the space below."

Data Analysis

The Statistical Package for the Social Sciences (SPSS) for Mac and SPSS Amos 22.0 for PC were used to manage all raw data and perform all data analyses. Data were analyzed using preliminary screening procedures, descriptive statistics, structural equation modeling, and hierarchical regression to test the hypothesized relationships. Scores on all measures were computed as mean item scores in order to assist in the meaningful interpretation of participant responses.

Preliminary screening. Prior to conducting analyses, the researcher conducted a preliminary screening of the data using SPSS. The purpose of the data screen was to: (a) ensure the accuracy of data entry; (b) replace and/or manage missing data; (c) transform scores as necessary, and (4) screen for univariate outliers, univariate normality, and multivariate outliers. Participants who did not meet the inclusion criteria were excluded from the analysis; the survey automatically terminated if participants did not self-report to meet the inclusion criteria. Item completion rates were determined using the Missing Data Analysis function in SPSS. Item non-completion rates were quite low, ranging from 0% to 1.3%. While there is no well-established cut-off percentage for missing data, Schafer (1999) stated that a missing data rate of 5% or less is considered to be negligible in the interpretation of results. Others have provided more forgiving cut-off percentages; for example, Bennett (2001) asserted that a missing data rate of 10% or higher will likely lead to biased results. Given the low rates of missing data in the present study, incomplete data were replaced using mean imputation.

Once missing data were replaced, variables were screened for univariate outliers (greater than 3.29 standard deviations from the mean (Tabachnick & Fidell, 2007). Univariate outliers were removed from the dataset; there were three outliers in total. Data were examined for univariate normality. Based on Kline's (2011) recommendations, criteria for univariate normality was a skew between -2.0 and 2.0 and kurtosis between -7.0 and 7.0. Finally, data were analyzed for multivariate outliers using Mahalanobis distance values, which depend on the number of variables used in the data analysis. Based on the number of variables used, a critical chi-square value was computed (Tabachnick & Fidell, 2007) in order to screen for multivariate outliers. The Mahalanobis distance analysis in the present study included 12 variables; thus, the critical chi-square value was 22.36. Participants with a Mahalanobis distance values greater than 22.36 were removed from the quantitative analyses; in total, 2 multivariate outliers were removed from the analyses.

Descriptive statistics. Descriptive statistics were computed for all independent and dependent variables in this study to describe the sample demographics and the research variables used in the analysis. Frequencies and percentages were calculated for nominal data and means and standard deviations were calculated for continuous data. All sample demographic and scale variables were reported with descriptions of central tendency (e.g. mean), variability (e.g. standard deviations), and distribution (e.g. normality, skewness, kurtosis). In addition to these analyses, a Cronbach's alpha coefficient was computed for each measure as an estimate of the scale's internal consistency reliability for the sample used in this study. Lastly, an inter-correlation matrix including correlation coefficients among scores on all scales was computed to determine the bivariate correlations between all observed variables, which assisted in assessing and identifying multicollinearity between the variables included in this study.

Structural equation modeling. SPSS Amos software was used to perform SEM data analyses. SEM is a statistical procedure used to demonstrate how latent variables and observed variables interact with one another, as well as to determine if the proposed path model fits the sample data. SEM is a synthesis of two statistical techniques: factor analysis and path analysis (Weston et al., 2008). This statistical procedure has been increasingly utilized in rehabilitation research, particularly due to the biopsychosocial approach toward disability that requires investigators to consider a number of underlying factors influencing rehabilitation outcomes (Weston et al., 2008). Quintana and Maxwell (1999) indicate that there are four major advantages of using SEM procedures:

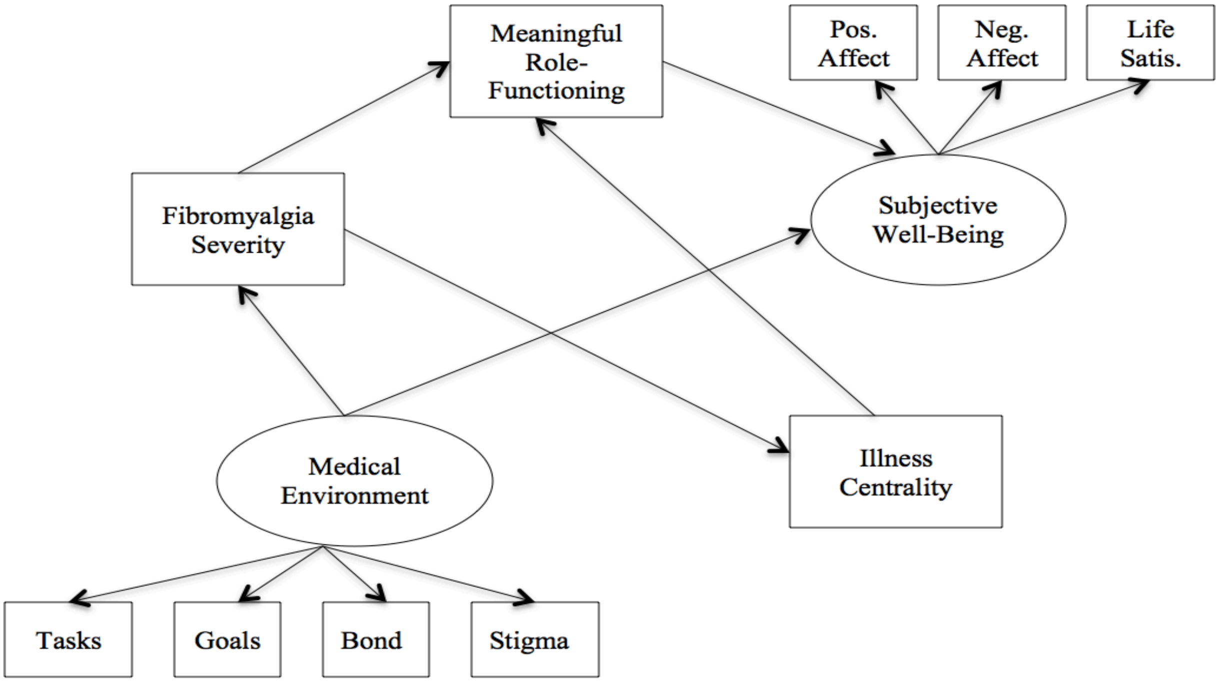
1. SEM allows for more choice and flexibility in representing theoretical relationships between constructs.
2. Using SEM, a collection of multiple observed constructs (e.g. stigma, physician-patient working alliance, and social support) can be used to represent a broader latent construct (e.g. socioenvironmental factors).
3. SEM tests the hypothesized model while also taking into account error. SEM can consequently be used to measure the validity of underlying constructs as well as the relationships between latent constructs.
4. SEM provides a statistical evaluation of general compatibility ("goodness of fit") of the model, as well as assesses the strength of the relationships between the constructs included in the model.

The present study sought to test a biopsychosocial model of quality of life in women with FMS, using feminist disability theory as a guiding theoretical framework. Given the broad biopsychosocial constructs identified (e.g. environmental factors, personal factors, and health condition factors), as well as the underlying, observed constructs classified into each of these broad factors affecting quality of life, SEM appeared to be the most appropriate statistical procedure to evaluate the hypothesized relationships between these variables. Figure 3.1 represents the hypothesized SEM model evaluated in this study.

In evaluating this model, the study followed the general guidelines for SEM outlined by Weston and colleagues (2008):

1. Model specification, which involves specification of observed and latent variables, as well as determination of hypothesized relationships using parameter values.
2. Model identification, which involves determining if the investigator can create a unique set of estimates for the parameters of interest.
3. Data collection and screening, which involves achieving an adequate sample size, addressing issues of multicollinearity, identifying outliers, assessing normality, and addressing missing data.
4. Model estimation, which involves estimating for each parameter the unstandardized coefficient, standardized coefficient, and standard error of the estimate.
5. Evaluation of model fit, which involves evaluation of model fit with sample data, as well as interpretation of parameter estimates.
6. Model modification, which involves respecifying the originally-hypothesized model to achieve a more ideal model-to-data fit.

Figure 3.1 The Proposed Structural Equation Model



Each of the pathways in the hypothesized model were included in the original structural equation model. To evaluate the model fit, as recommended by Weston et al. (2008), several fit indices were evaluated for adequacy. These indices included the chi-square goodness-of-fit test (a nonsignificant chi-square is considered acceptable), the ratio of the chi-square index to its degrees of freedom ($\chi 2/df$; values between 1 and 3 are considered acceptable), the comparative fit index (CFI; values >.95 are considered acceptable), and the goodness-of-fit index (GFI; values >.95 are considered acceptable). In addition, the Root Mean Square Error of Approximation (RMSEA) was evaluated. A RMSEA value of less than .05 indicates a close model fit and a value up to .08 indicates an acceptable model fit (Byrne, 2010). RMSEA confidence intervals were also assessed. For a RMSEA with 90% confidence intervals, the following general rules apply: a value of 0 is interpreted as an exact fit; values less than .05 are a close fit; values between .05 and .08 are a reasonable fit; values between .08 and .10 are a mediocre fit; and values more than .10 are considered a poor fit (Browne & Cudeck, 1993; Chan, Lee, Lee, Allen, & Kubota, 2007; Hu & Bentler, 1999; Weston et al., 2008).

Moderation Analysis. The Statistical Package for Social Sciences (SPSS) 22.0 for Mac was used to conduct the proposed moderation analysis. To test whether the chosen moderator buffers the effect of the predictor variable on the outcome variable, a hierarchical multiple regression analysis was conducted. First, to demonstrate that both the predictor and the moderator account for some of the variance in the outcome variable, the predictor and moderator was entered as independent variables and the outcome as the dependent variable. Next, an interaction term was created by multiplying the predictor variable by the proposed moderator variable. Frazier, Tix, and Barron (2004) stated that variables in a regression equation should always be centered or standardized in order to avoid high multicollinearity with the interaction terms created from them. Thus, in creating the interaction term, the standardized versions (z-scores) of both the predictor variable and the moderator were used. Finally, the interaction term was entered in the regression equation in order to compare how much of the variance in the outcome variable was accounted for by solely the interaction term, in absence of predictor and proposed moderating variable by themselves.

Research question 3 asks, “Does illness centrality moderate the relationship between FMS severity and life satisfaction?” To test whether illness centrality buffers the effect of FMS severity on life satisfaction, a hierarchical multiple regression analysis was conducted. First, to demonstrate that both illness centrality and FMS severity account for some of the variance in life satisfaction, illness centrality and FMS severity were entered as independent variables and life satisfaction as the dependent variable. Next, the z-scores of illness centrality and FMS severity were multiplied by one another to create an interaction term. Finally, the interaction term was entered in the regression equation in order to compare how much of the variance in the life satisfaction was accounted for by solely the interaction term, in absence of illness centrality and FMS severity alone.

CHAPTER 4

Results

The purpose of the present study was to identify the direct and indirect predictors of SWB in women with fibromyalgia (FMS) using a feminist, biopsychosocial framework of disability. Structural equation modeling was used to determine if the proposed model fit the empirical data, whether a modified model provided an improved model-to-data fit, and the relationships among variables in the model. Based on a framework of chronic illness and disability informed by feminist disability theory, the following variables were chosen to represent the biopsychosocial constructs included in this research: (a) biological factors were represented by FMS severity; (b) psychological factors were represented by illness centrality; (c) socioenvironmental factors were represented by the medical environment, including the tasks, goals, and bond subconstructs of physician-patient working alliance; (d) participation was represented by meaningful role-functioning; and (e) SWB was represented by positive affect, negative affect, and life satisfaction. In addition, one hierarchical regression analysis was conducted to evaluate the moderating effect of illness centrality on the relationship between FMS severity and life satisfaction.

Structural Equation Model

Descriptive data for all variables included in this research study, including the MRFQ construct validation, are provided in Table 4.1. Intercorrelations among the variables in the hypothesized structural equation model are shown in Table 4.2. Significant correlations ranged from .076 to .868, with most correlations significant at the $p<.01$ level. Positive affect did not correlate significantly with the tasks or goals subconstructs of physician-patient working alliance.

Proposed model. Research question 1 asked, “using structural equation modeling, does the SWB model based on a feminist, biopsychosocial framework of disability fit the data collected among women with fibromyalgia?” The hypothesized model (Model 1), shown in Figure 4.1, was evaluated using SEM analysis. The inclusion of physician stigma in the proposed model resulted in a statistical program error in evaluating the model itself; this error was likely due to the fact that, despite theoretical predictions, physician stigma correlated very weakly with physician-patient working alliance, indicating that the two constructs were not well-suited to represent a broader latent construct. Thus, physician stigma was removed from the model entirely, leaving the tasks, goals, and bond subconstructs of physician-patient working alliance to represent the medical environment. The model tested revealed a significant chi-square and an inadequate relative chi-square value (χ^2=155.29, $p < .001$; χ^2/df=6.47; N=229). Additionally, other fit indices were found to indicate an inadequate fit of the model to the data (GFI=.89, CFI=.89, and RMSEA=0.12). The proposed model failed to support the hypothesized direct relationship between the medical environment and SWB. All other hypothesized paths were found to be statistically significant. Because the model fit was inadequate model modification indices were examined to determine whether there were theoretically justified respecifications that would improve model fit.

Table 4.1 Descriptive Statistics for Study Measures (*n*=229)

Biopsychosocial Constructs	**Instrument (# Items)**	**Min.**	**Max.**	***M* (*SD*)**	**Reliability Coefficient**
Health Condition Factors					
FMS Severity	Revised Fibromyalgia Impact Questionnaire - Total (21)	22.50	96.17	70.26 (16.00)	.94
Psychological Factors					
Illness Centrality	Illness Self-Concept Scale - Total (23)	30	122	70.92 (19.46)	.93
Socioenvironmental Factors					
Physician Stigma	Chronic Pain Stigma Scale (Physician subscale) - Total (10)	20	60	41.45 (8.57)	.85
Physician-Patient Working Alliance	Physician-Patient Working Alliance - Total (12)	15	84	57.93 (17.02)	.92
	• Tasks (3)	3	21	13.96 (4.54)	
	• Goals (4)	4	28	18.96 (5.75)	
	• Bond (5)	5	35	25.00 (7.53)	
Participation					
Meaningful Role-Functioning	Meaningful Role-Functioning Questionnaire - Total (20)	1	5	3.00 (.94)	.74[a]
SWB					
Life Satisfaction	SWLS Total (5)	5	31	14.39 (6.81)	.85
Positive and Negative Affect	PANAS Total (20)				
	• Positive Affect (10)	10	49	23.45 (8.15)	.91
	Negative Affect (10)	11	50	28.92 (9.75)	.91
MRFQ Validation Variables					
Core Self-Evaluations	Core Self-Evaluations Scale - Total (12)	12	53	32.14 (8.29)	.86
Social Support	Multidimensional Scale of Perceived Social Support - Total (12)	1	7	4.60 (1.34)	.92
Chronic Pain Stigma	Chronic Pain Stigma Scale - Total (30)	18	56.67	39.31 (8.15)	.90
Participation in Society	WHODAS 2.0 – Participation Subscale (8)	2	32	18.71 (6.21)	.86

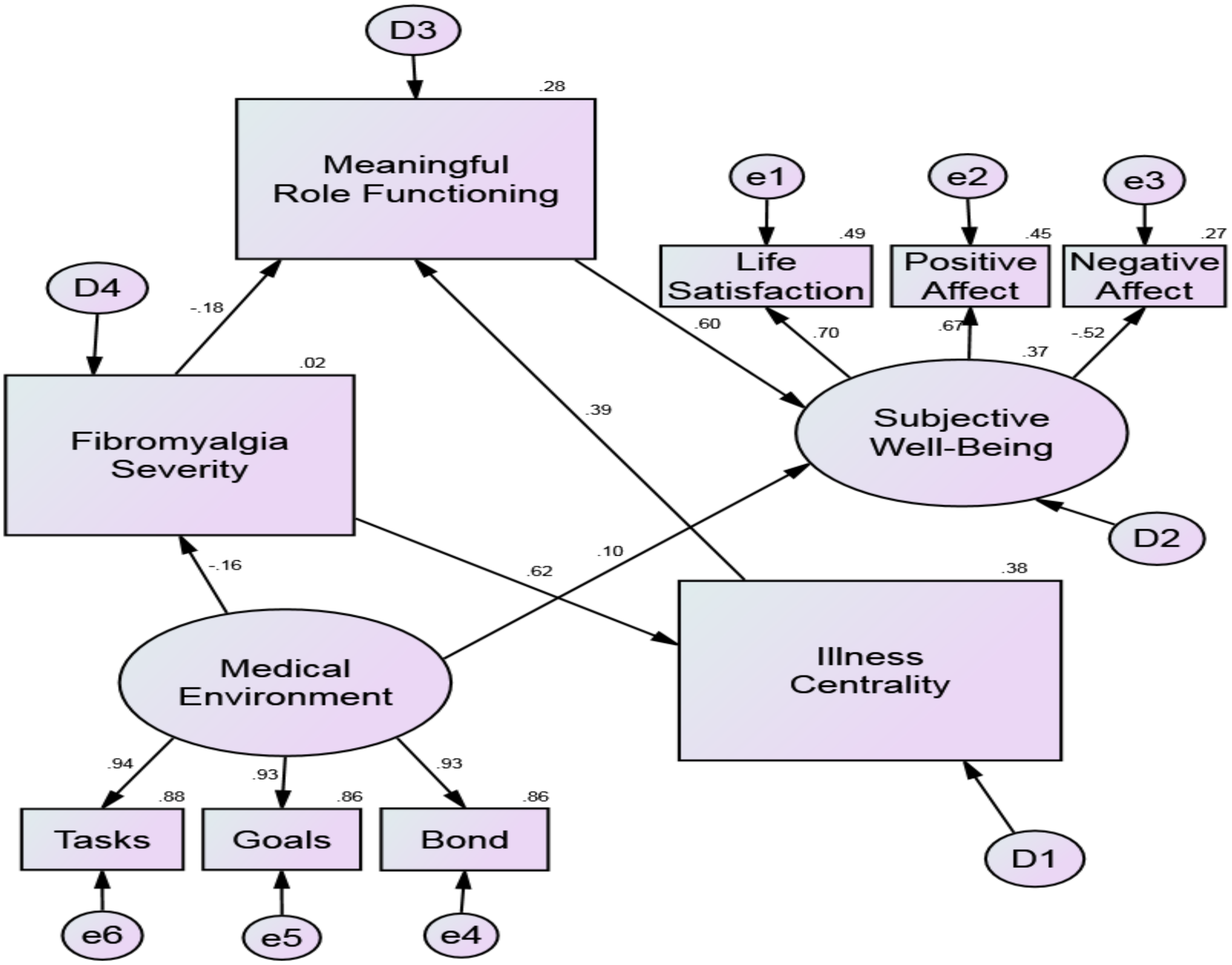
Note. [a]test-retest reliability coefficient

Table 4.2 Intercorrelations for Variables Used in Structural Equation Model (*n*=229)

Variable	1	2	3	4	5	6	7	8	9	10
1. FMS Severity	1	--	--	--	--	--	--	--	--	--
2. PPWA - Tasks	-.157*	1	--	--	--	--	--	--	--	--
3. PPWA- Goals	-.161*	.868**	1	--	--	--	--	--	--	--
4. PPWA - Bond	-.077	.872**	.863**	1		--	--	--	--	--
5. Physician Stigma	.049	-.107	-.086	-.144*	1					
6. Illness centrality	.625**	-.209**	-.202**	-.117	.101	1	--	--	--	--
7. Meaningful Role-Functioning	-.413**	.243**	.221**	.217**	-.195*	-.520**	1	--	--	--
8. Positive Affect	-.441**	.113	.076	.139*	-.108	-.402**	.440**	1	--	--
9. Negative Affect	.543**	-.210**	-.194**	-.173**	.072	.478**	-342**	-.328**	1	--
10. Life Satisfaction	-.570**	.181**	.185**	.141*	-.101	-.519**	.423**	.482**	-.382**	1

Note: *$p < .05$; **$p < .01$; PPWA = Physician-patient working alliance

Figure 4.1 The Hypothesized Structural Equation Model (*n*=229)



Model modifications. To determine modifications, the researcher examined the critical ratio value for eliminating paths, along with the modification indices for adding paths to the model. Because the proposed model failed to support the hypothesized direct relationship between physician-patient working alliance and SWB, this path was eliminated. After careful consideration of modification indices and relevant theory (Kline, 2011; Quintana & Maxwell, 1999), two paths were added: (a) a direct path from FMS severity to SWB; and (c) a direct path from illness centrality to SWB. The results demonstrated a good fit of the respecified model to the data. While the chi-square index was still found to be statistically significant (χ^2=54.13, $p <$ .001), other fit indices indicated an adequate model fit (χ^2/df=2.35; GFI=.95; CFI=.97; RMSEA=.08). Figure 4.2 shows a schematic depiction of the respecified model (Model 2) with standardized path coefficients and the squared multiple correlation coefficients (R^2). Table 4.7 indicates goodness-of-fit and modification indices for Models 1 and 2.

The R^2 for endogenous variables in the respecified model ranged from .02 to .79. FMS severity, meaningful role-functioning, and illness centrality accounted for 79% of the variance in SWB. The effects of physician-patient working alliance on SWB (hypothesized to be direct in the initial model) were only indirect in the final model, with FMS severity as the mediator. FMS severity and illness centrality accounted for 28% of the variance in meaningful role-functioning, with the indirect effect of physician-patient working alliance. FMS severity accounted for 38% of the variance in illness centrality. Lastly, physician-patient working alliance accounted for 2% of the variance in FMS severity.

Results from the effects analysis demonstrated that FMS severity (β = -.53, p < .001), meaningful role-functioning (β = .24, p < .001), and illness centrality (β = -.28, p < .001) all had significant, direct effects on SWB. Thus, individuals with lower levels of illness severity, higher reported functioning in meaningful life-roles, and illness appraisals more peripheral to the core self reported higher levels of SWB. FMS severity (β = -.18, p < .05) and illness centrality (β = -.39, p < .001) had significant, direct effects on meaningful role-functioning. Thus, individuals with lower levels of illness severity and perceptions of illnesses more peripheral to the core self reported better perceived functioning in meaningful life roles. FMS severity also had a significant, direct effect on illness centrality (β = .62, p < .001), meaning that individuals with lower levels of illness severity reported illness appraisals that are more peripheral to the core self. Physician-patient working alliance had a significant, direct effect on FMS severity ($\beta = -.16$, $p < .05$), indicating that individuals with a better reported working alliance with their physician or primary FMS care provider reported slightly lower levels of illness severity.

Indirect effects were also assessed using a bootstrapping analysis in SPSS AMOS. Physician-patient working alliance had significant indirect effects on illness centrality through fibromyalgia severity ($ab = -.10$, $p < .01$), meaningful role-functioning through fibromyalgia severity ($ab = .07$, $p < .01$), and SWB through fibromyalgia severity and illness centrality ($ab = -.13$, $p < .01$). FMS severity had significant indirect effects on meaningful role-functioning through illness centrality ($ab = -.243$, $p < .01$), and SWB through illness centrality ($ab = -.279$, $p < .05$). Lastly, illness centrality had a significant indirect effect on SWB through meaningful role-functioning ($ab = -.095$, $p < .01$).

Figure 4.2 The Respecified Structural Equation Model *(n*=229)

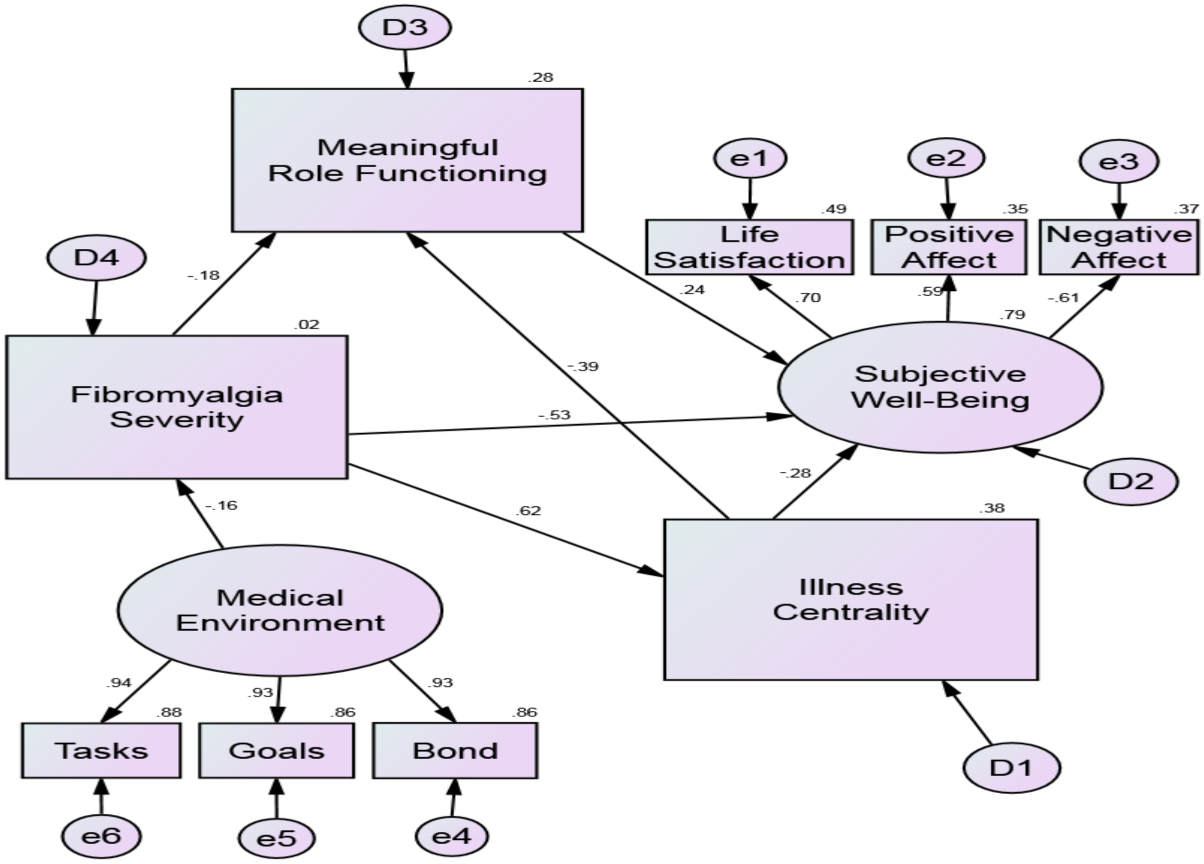


Table 4.3 Model Goodness-of-Fit Indices in Original and Modified Models (*n*=229)

Model	**Paths Modified**	χ^2	χ^2/df	**GFI**	**CFI**	**RMSEA**[a]
1	--	155.29	6.47	.89	.89	1.55 (.13, .18)
2	-Removed medical environment → SWB -Added FMS severity → SWB -Added Illness centrality → SWB	54.13	2.35	.95	.97	0.08 (.05, .10)

Note. χ^2/df = ratio of chi-square to its degrees of freedom; GFI = goodness of fit index; CFI = comparative fit index; RMSEA = root mean square error of approximation; [a]Lower and upper estimates within 90% confidential interval (CI) are listed in the parentheses.

Moderation Analysis

Intercorrelations for the variables included in the moderation analysis are provided in Table 4.4. Table 4.5 provides coefficients and outcome variance information for each step of the hierarchical regression. Moderation in the present study was not supported by the data. In the first step of the regression analysis, FMS severity and illness centrality accounted for a significant amount of the variance in life satisfaction **(**R^2=.37, $F(2, 225) = 65.59$**,** $p < .001$). When the interaction term between FMS severity and illness centrality was entered in the second step of the regression analysis, the interaction term did not explain a significant amount of the variance in life satisfaction ($\Delta R^2 = .008$, $F(3, 224) = 44.6$, $p = .097$).

Table 4.4. Intercorrelations for Variables Used in Moderation Analysis (*n*=229)

Variable	1	2	3
1. FMS severity	1	--	--
2. Illness centrality	.625**	1	--
3. Life Satisfaction	-.570**	-.519**	1
4. Product term	-.325	.177**	.260**

Note: *$p < .05$; **$p < .01$.

Table 4.5 Hierarchical Regression Coefficients for Moderation Analysis (*n*=229)

	Variable	β	R^2	ΔR^2
Model 1	FMS severity	-.403***	.368	--
	Illness centrality	.267***		
Model 2	FMS severity	-.168***	.376	.008
	Illness centrality	.095***		
	Product term	-.541 (*n.s.*)		

Note: ***$p < .001$

MRFQ: External Correlates

Research question 4 addressed whether meaningful role-functioning correlates with other important measures and predictors of participation and SWB. the MRFQ was developed by the author as a theory-based measure of role functioning, and it is important to examine evidence for its external validity; thus, correlations with other important predictors and indicators of participation were examined. Table 4.6 provides intercorrelations between the MRFQ and the other variables in question. All correlations were significant and indicated relationships in the expected directions. Using the guide provided by Cohen (1988) results from the correlation analysis yielded the following results: (a) strong, positive, and significant correlations between the MRFQ and illness centrality ($r = -.520$, $p<.01$), core self evaluations ($r = .539$, $p<.01$), positive affect ($r=..440$, $p<.01$), and life satisfaction ($r = .423$, $p<.01$); (b) strong, negative, and significant correlations between the MRFQ and participation in society ($r = -.500$, $p<.01$) and FMS severity ($r = -.413$, $p<.01$); (c) a moderate, positive, and significant correlation between the MRFQ and perceived social support ($r = .318$, $p<.01$); (d) a moderate, negative correlation between the MRFQ and negative affect ($r = -.342$, $p<.01$); and (e) a weak, negative correlation between the MRFQ and chronic pain stigma ($r = -.165$, $p<.01$).

Table 4.6 MRFQ External Correlates

Variable	**Correlation with Meaningful Role-Functioning (MRFQ)**
Participation in Society (WHODAS 2.0 Participation in Society subscale)	-.500**
FMS Severity (FIQR)	-.413**
Illness Centrality (ISCS)	-.520**
Core Self-Evaluations (CSES)	.539**
Perceived Social Support (MSPSS)	.318**
Chronic Pain Stigma (CPSS)	-.165**
Positive Affect (PANAS Positive Affect scale)	.440**
Negative Affect (PANAS Negative Affect scale)	-.342**
Life Satisfaction (SWLS)	.423**

Note: ***p* < .01.

CHAPTER 5

Discussion

Women with chronic illness and disability face a multitude of challenges in their everyday lives, challenges that are rooted in social definitions of illness and normality, gendered expectations and stereotypes, and biological complications associated with the illness or disability itself. While gender and disability are traditionally viewed as separate identities, the intersection of femaleness and chronic illness and disability cannot be understated; women with FMS are especially affected by this identity intersection, as the lack of scientific evidence for their illnesses and the ambiguities of both FMS etiology and symptoms challenge the traditional medical model of disability. Moreover, their status as women, combined with an ambiguous, stigmatized illness, makes them uniquely vulnerable to social disregard by the general public, social networks, and medical professionals.

Rehabilitation scholars have long advocated for the use of biopsychosocial models to explain the disability experience, while feminist disability scholars have similarly challenged the traditional medical model of disability, arguing that the impact of chronic illness and disability are not based in biological factors alone; rather, socioenvironmental factors equally, if not disproportionately, affect the illness and disability experience, thereby influencing psychological well-being and overall quality of life. Feminist disability scholars in particular challenge the notion that the female experience and the disability experience, separately, are universal to all women and to all persons with disabilities; rather, the theory assumes that gender and disability relate in ways that interactively influence the lives of women with disabilities. While the goals and objectives of the biopsychosocial and feminist conceptualizations of illness and disability share important themes, the integration of these theories in both the feminist and disability literature is limited. The purpose of the current study was to employ a feminist, biopsychosocial framework of chronic illness and disability to predict SWB in women with FMS. The following sections will provide a summary of the major findings of this study based on each study aim, address any study limitations that may affect the interpretability of results, and review implications for rehabilitation research and practice.

Summary of Findings

Structural equation model. The overall objective of the present study was to evaluate a feminist, biopsychosocial model of the predictors of SWB in women with FMS. Based on a comprehensive review of the literature, as well as relevant theory, several primary variables were included to address the central purpose of the study. The investigator used structural equation modeling to examine the combined effects of FMS severity, the medical environment (physician-patient working alliance; physician stigma), illness centrality, and meaningful role-functioning on SWB in a sample of women with FMS. Specifically, it was hypothesized that the proposed feminist, biopsychosocial framework would fit the data in the current sample. In terms of direct predictive relationships, it was further hypothesized that the following direct paths would be significant in the structural equation model: (a) medical environment directly predicting FMS severity; (b) medical environment directly predicting SWB; (c) FMS severity directly predicting meaningful role-functioning; (d) FMS severity directly predicting illness centrality; (e) illness centrality directly predicting meaningful role-functioning; and (f) meaningful role-functioning directly predicting SWB.

The study findings revealed that the proposed model (Model 1) did not yield an adequate model-to-data fit. As noted, the inclusion of physician stigma in the proposed model resulted in a statistical program error in evaluating the model itself; thus, physician stigma was removed from the model entirely, leaving the tasks, goals, and bond subconstructs of physician-patient working alliance to represent the medical environment. To improve model fit via respecification, the investigator consulted both the model modification indices provided by the statistical software, as well as relevant literature. The resulting modifications included the following removal and addition of paths: (a) the nonsignificant path from the medical environment to SWB was removed; (b) a direct path from FMS severity to SWB was added and (c) a direct path from illness centrality to SWB was added.

The respecified model (Model 2) indicated an acceptable model-to-data fit. In this model, FMS severity, meaningful role-functioning, and illness centrality all significantly and directly predicted SWB. FMS severity in particular appeared to critically influence SWB, indicating that functional status and symptom severity indeed play important roles in overall well-being. Importantly, the respecified model indicated that this relationship was mediated by both meaningful role-functioning and illness centrality. These results suggest that an individual's evaluation of her functioning in life roles that are subjectively important may partially explain the relationship between illness severity and well-being. In other words, the model implies that women with lower levels of illness severity will evaluate their functioning in life roles more positively, and thus, will experience higher levels of positive affect, lower levels of negative affect, and better satisfaction with life as a whole. Similarly, persons with lower levels of illness severity will perceive her illness as more peripheral to the core self, and will ultimately have better SWB. Illness centrality also directly predicted meaningful role-functioning, suggesting that women who perceive their illnesses as less intrusive and dominant in their lives will hold better appraisals of their functioning in significant life roles, again positively influencing SWB.

As noted, the direct path from the medical environment to SWB was removed in the respecified model. Furthermore, while the hypothesized path between the medical environment and FMS severity was found to be significant, the effect was quite weak. The marginal effects of variables representing the medical environment in the present research model are notable findings; based on the feminist theoretical framework, it was expected that these particular factors would play important roles, either directly or indirectly, in predicting SWB. While these results may indicate a genuinely minimal effect of the medical environment on well-being, previous findings suggest that women and women with ambiguous, stigmatized diagnoses indeed face environmental barriers to adequate healthcare. In a qualitative study examining the ways in which women with FMS interpret their symptoms, Dennis et al. (2013) found that doctors played an important role in the lives of women with FMS, with participants expressing low expectations for and unfulfilling relationships with medical providers, feeling that their doctors were "clueless" about FMS. Other research has demonstrated that women with FMS, and women in general, struggle to gain validation and trust from doctors when seeking care for physical symptoms, as doctors commonly attributed these symptoms to a psychological cause (Armitage, Schneiderman, & Bass, 1979; 1981; Åsbring and Närvänen, 2002; Bernstein & Kane, 1981).

Considering the somewhat conflicting findings between the present study and previous research, the investigator consulted participant responses to the open-ended prompts included in this study, which were intended to aid in the interpretation of quantitative results. These responses should be interpreted with caution, as any empirical claims would require a more sophisticated qualitative analysis. However, these responses indicate that further inquiry into the investigation and measurement of women's experiences with medical personnel is justified. The current participants' accounts of experiences with medical providers somewhat mirror those found in past qualitative research, shedding further light on the nature of FMS as a gendered illness associated with stereotypically female traits (e.g. highly emotional, depressed), and gendered trait expectations from others (e.g. passivity, or low assertiveness), particularly in medical settings. Some respondents expressed a perceived lack of understanding and empathy on the part of physicians and other medical providers, experiences complicated by physicians' hastiness to attribute symptoms to psychological dysfunction. One participant stated,

> Most people feel that my pain is 'all in my head' and that if I just pushed myself I could do everything they can….they view me as weak, and as a complainer. Doctors as well are not empathetic and really don't understand what it means to live with chronic pain and FMS.

Other respondents expressed feeling patronized, belittled, and invalidated by medical professionals. For instance, one respondent said,

> I believe that most medical professionals treat me like I don't know anything about my own body and illness,

while another stated,

> I feel doctors don't take me seriously [and] are too quick to blame my physical issues on emotional or mental problems.

Many respondents expressed concerns regarding the intersection of gender and illness, experiences that are substantiated by the literature demonstrating that women are uniquely exposed to social and systemic barriers in medical settings. These responses were underscored by perceptions that medical professionals viewed legitimate physical symptoms as psychosomatic in nature. For example, one participant stated, "I feel sometimes my communication with doctors is thought of as emotional and is not taken the same way as if a man were saying the same things." Others described their experiences of the intersection of illness, gender, and age:

> I do believe health professionals do not listen, have deep prejudices, and cannot objectively evaluate an intelligent women over 50… this is why fibro sufferers have such a bad reputation, they are overreacting to lack of validation in my opinion. They then come across as whiners.

Another participant shared,

> I'm a post menopausal woman of 55 I feel that most older male doctors see my health problems as being 'typical' and some of the younger female professionals can be a little patronizing.

Participants also voiced experiencing aggravated responses from medical providers. One respondent articulated these sentiments, also referencing a lack of agreement upon treatment tasks and goals:

> When I first got sick, I felt….that my concerns were not being given as much credence as a man's would have. Older, male doctors were less likely to involve me in their idea of a treatment plan…. With several practitioners, I was considered problematic for wanting information on a medication before trying it. Eye rolling, sighing, etc. -- right in front of me. One practitioner (male, M.D.) gave me a book recommendation, which turned out to be about how unresolved anger makes chronic illness.

One participant echoed the concerns of others, while also stating that she no longer engages with the medical system due to her experiences:

> Pain is taken less seriously when it is coming from a woman. Not only that, but so are my opinions of my medical care. I do a lot of research and read research papers pertaining to

> FMS and when I try to present them to my Dr's I am brushed aside. I no longer go, as I am never listened to.

A select few respondents conveyed having good, trusting relationships with medical providers; however, the women expressing tense, distrustful relationships critically outnumbered those who did not.

Given these accounts of participants' experiences in medical settings, it seems interesting that the quantitative measures failed to capture a more robust effect of the medical environment in the present research model. After further consideration, several explanations for these results emerge. Prior research has demonstrated that physician-patient working alliance is a significant predictor of health-related quality of life (HRQOL; Bennett, Fuertes, Keitel, & Phillips, 2011). Contextualizing the present results within past findings indicates that physician-patient working alliance may be more strongly predictive of both broad and specific health-related outcomes, as opposed to overall well-being. Furthermore, health outcomes (e.g. HRQOL; illness severity) may fully mediate the relationship between the working alliance and SWB. In this study, the working alliance was a significant, direct predictor of FMS severity, which then directly and significantly predicted SWB. The mutual trust and bond, as well as mutual agreement upon tasks and goals, may influence the severity of FMS symptoms, the functional impact of the illness, and the overall impact of the illness on the individual's life, thereby influencing SWB.

Again, the above findings should be considered in light of prior research. Further review of the literature indicates that the present study may have excluded important constructs significant to the relationship between working alliance and health-related outcomes. Bennett et al. (2011) found that in a sample of 190 individuals with lupus, physician-patient working alliance significantly predicted both treatment adherence and treatment satisfaction; treatment satisfaction mediated the relationship between the working alliance and HRQOL. Additional research indicates that other environmental and psychological factors, such as physician empathy, physician cultural competence, and self-efficacy should be taken into account when considering the relative impact of the working alliance on outcomes. In a sample of 190 neurology patients, Fuertes et al. (2007) found moderate effect sizes between working alliance ratings and patients' perceived utility of treatment and adherence self-efficacy beliefs. Furthermore, the authors found that physician-patient working alliance significantly predicted patient satisfaction with their healthcare. However, in that particular study, findings indicated that working alliance did not significantly predict treatment adherence above and beyond the effects of physician empathy, physician multicultural competence, and patients' treatment adherence self-efficacy. These findings were in contrast to research supporting a strong relationship between the working alliance and treatment adherence (Bennett et al., 2011; Fuertes et al., 2006). Considering these mixed findings, along with the results of the present study, future research is warranted to identify the relationships between these variables in order to determine if other relevant psychological and environmental factors indeed interact with or supersede the effects of the working alliance to affect health and quality of life outcomes in women with FMS.

In addition, the present results may be explained by the diffuseness of the measures used to evaluate this broader construct. Most notably, the survey instructed participants to respond to statements regarding medical professionals in response to either: (a) any doctor or medical professional who had treated her in the past for the CPSS, or (b) the primary medical professional she sees for her FMS symptoms for the PPWA. Particularly given the range of diverse symptoms associated with FMS, persons with this diagnosis may see several primary providers for FMS-related symptoms, and points of reference for each participant may have varied based on a number of important factors, including the frequency of visits, the level of familiarity with the provider, and the duration of the relationship at the time of the survey; variability among these factors may have influenced the results of this study. Future research should consider and account for the influence of potential confounding factors in attempting to quantitatively measure aspects of the medical environment.

Moderation analysis. Research question 3 asked: “Is illness centrality a significant moderator of the relationship between FMS severity and life satisfaction?” Moderation in the present study was not supported by the data; in other words, the relationship between fibromyalgia severity and SWB was not significantly different for individuals with illnesses more peripheral to the core self and illnesses more central to the core self. This result indicates that independent of illness centrality, functioning levels, symptom severity, and the overall impact of the illness will significantly affect life satisfaction, and this relationship will not change based on the centrality of the illness to the core self. However, as noted, illness centrality was a significant mediator of the relationship between FMS severity and life satisfaction, so it can still be interpreted as a relevant psychological variable to assess within a biopsychosocial framework.

MRFQ findings. One of the main goals of this study was to measure participation in a way that accounts for the life roles and areas that are subjectively important to the individual. The investigator developed a new instrument called the Meaningful Role-Functioning Questionnaire (MRFQ), which measures two primary subconstructs: *perceived role-importance* and *perceived role-fulfillment*; taken together, the subscores on these constructs yield a total role-functioning score that weighs life roles identified as more important to the individual more heavily than those that are less important. The scale demonstrated good test-retest reliability

(.74), particularly given the population on which the scale was validated. FMS symptoms tend to be relatively unstable, with periods of remission and periods of symptom flare; thus, high consistency in responses over a period of one month was not necessarily expected. While further research is warranted to confirm these results, future users of the MRFQ may accept meaningful role-functioning as a relatively stable construct in persons with FMS.

For validation purposes, the external correlates of the MRFQ were also evaluated. The correlation with the WHODAS subscale was a concurrent validity correlation with scores on another measure of the same construct. The $r = .5$ indicates a reasonable level of agreement between the two scales. Other measures were included based on the investigator's understanding of what Cronbach and Meehl (1955) referred to as the "nomological network" of constructs related to meaningful role-functioning. For example, symptom severity, illness centrality, and core self-evaluations likely impact people's ability and motivation to engage in meaningful life activities. These predictions were supported by substantial correlations between measures of these constructs and scores on the MRFQ. Similarly, participation in meaningful roles should be associated with improved quality of life, a prediction supported by strong correlations between MRFQ and PANAS/SWLS. Results were generally in line with what was anticipated, although stronger correlations were expected between the MRFQ and environmental factors such as social support and chronic pain stigma. These correlations may have been weak due to the scope of life areas or relationships covered in each scale. For instance, the MRFQ measures functioning in a range of life-roles (e.g. parent, son/daughter, worker, friend), while the MSPSS measures perceptions of support from only friends, family, and significant others, and the CPSS measures perceived stigma from the general public, family, and doctors/medical professionals.

Limitations

In interpreting the results of this study, several limitations should be acknowledged. First, while SEM implies directionality in relationships, it is not possible to infer causality or directionality from these results, given the cross-sectional nature of the study. The results may represent biased parameter estimates, as participant responses may have been influenced by the particular time of survey administration. Second, several factors limit the generalizability of the results. The sample primarily comprised White and well-educated women. A majority of the sample reported being employed (full-time or part-time) or retired, and most of the individuals were insured either through their own or a spouse's or family member's employer. In addition, all participants were recruited via an online format (i.e. social media or an organization website); thus, it may be inferred that the individuals participating in this survey had greater access to online services and/or represented women with more familiarity with the skills to navigate the online survey process. Furthermore, individuals who were not seeking support or community from a fibromyalgia-related social media page or website were not represented in this sample. In addition, the length of the survey may have deterred individuals with lower levels of functioning (e.g. higher levels of pain, fatigue, cognitive difficulties, and sleep problems) from participating. Also important to note, this study assumed a traditional gender binary, only asking participants to report if they identified as women. No attempt was made to delineate the unique experiences of those who fall on varying lines of the gender spectrum from those who identify with the gender they were assigned at birth (e.g. transgender women vs. cisgender women).

Measurement issues and instrument selection limitations may have further affected the results of the study. First, this study reflects only one interpretation of the biopsychosocial approach toward disability. There are variables not included in the primary research model (e.g.

environmental factors such as social support and stigma; personal, psychological factors such as coping, self-esteem, and self-efficacy; demographic covariates such as age, race/ethnicity, and income level) that may also interact with, explain, or confound the relationships between the variables in the present model. Several of the scales in this survey, namely the FIQR (measuring fibromyalgia severity) were chosen for brevity of the instrument, potentially affecting quality of measurement. Additionally, the scales used represent highly subjective dimensions of the constructs in question. For example, the chronic pain stigma scales represent perceived stigma, which may not be accurate representations of actual stigma. In addition, this is a self-report survey, and is thus vulnerable to bias and error. As noted, the survey was quite lengthy, which had the potential to result in participant fatigue, particularly in this disability population. Increased fatigue and cognitive difficulties amongst participants may have influenced certain individuals' ability to reliably self-report. Lastly, the scale used to measure role-functioning (MRFQ) was a novel scale developed by the investigator and has not been subject to an in-depth scale validation analysis, so results involving this scale should be interpreted with caution. In addition, in response to an open-ended prompt, many participants noted other important life roles not included in the questionnaire (e.g. grandparent, pet owner). Future research should seek to refine and validate the MRFQ as a subjective measure of participation and role-functioning in persons with FMS and other disabilities.

Implications for Rehabilitation Research and Practice

FMS is a complex disorder that has been subject to much controversy due to its ambiguous nature, subjective manifestation, and often-unsuccessful treatment. Persons with this diagnosis, particularly women, experience a great deal of frustration, stress, and relational dissatisfaction in their daily lives. FMS is especially unique, as the intersectionality of the diagnosis extends beyond gender and illness alone; the highly stigmatized nature of FMS complicates the processes through which women with this diagnosis are able to achieve full inclusion in social and community life and overall well-being. The present study sought to employ a feminist, biopsychosocial framework of chronic illness and disability by placing a particular emphasis on the medical environment, a social space in which problematic attitudes affecting women with FMS are widespread. The results of the present study have significant implications for rehabilitation clinicians and researchers seeking to better understand and address the challenges women with FMS face in their everyday lives. The findings in this study extend the current literature on the biopsychosocial factors that influence well-being in women with FMS, reinforcing the notion that SWB is more powerfully predicted by accounting for the joint influence of health condition, socioenvironmental, and psychological factors, as opposed to any of the single factors alone.

This study further provides context for evaluating a biopsychosocial model through a feminist lens. While several qualitative studies have utilized a feminist framework for evaluating inclusion and well-being in women with FMS, no known studies have explicitly used feminist disability theory to guide the quantitative, biopsychosocial evaluation of SWB in this population. Although the present research model accounted for a reasonably large amount of variance in SWB, the key feminist variables included in the model (physician-patient working alliance and physician stigma) did not appear to play a highly significant role in influencing the results; along with the measurement issues discussed above, the current results interpreted in light of past findings indicate that there may be a reason that past researchers have not endeavored to examine the feminist framework quantitatively. At present, the measures available to evaluate social spaces such as a medical environment may not be comprehensive enough to convey the very significant and nuanced experiences of women with FMS in these disabling environments. In the future, researchers should engage in close examination of the qualitative literature in order to inform the development of quantitative measures that are comprehensive enough and relevant to the experiences of women with chronic, ambiguous, and stigmatized conditions. Future investigation should also focus on employing a participatory action research approach in which women with FMS are included in all levels of the research process in order to better account for the most salient concerns of women with this diagnosis (Banks, 2010).

Despite the present results, feminist disability theory remains a useful framework for case conceptualization in rehabilitation counseling practice. Counselors may turn to the existing qualitative literature to provide context for working with women with FMS through a feminist lens. Past research has demonstrated that women with chronic illnesses must constantly adapt to, negotiate, and interact with the social environment in ways that are intimately connected to the intersection of their gender and illnesses. Inadequate access to health information resources, feelings of disempowerment in the medical environment, perceived lack of control over treatment options, and dependence upon a medically-legitimized diagnosis become central in the lives of women with chronic and ambiguous conditions. In examining a feminist conceptualization of disablement in women with chronic illnesses through qualitative interviews, Crooks and Chouinard (2006) found that medical spaces in particular had extensive and far-reaching effects on the navigation of life spaces outside of the medical environment. The emotional damage of feeling disempowered and delegitimized in the medical environment, where one expects to have health concerns legitimized or explained, carried over into the participants' interpretations of their experiences in other social spaces such as home and the workplace. The researchers found that the women interviewed hoped to use information provided by medical personnel to educate and share knowledge with others about their conditions. In working with women with FMS, rehabilitation counselors should assess client satisfaction with and experiences in health care spaces, as the emotions attached to these experiences may predict the ways in which they feel empowered to navigate other social spaces. Moreover, with the knowledge that interactions and experiences in potentially disempowering healthcare spaces may affect client behaviors and interpretations of events in other spaces, rehabilitation counselors should be proactive in encouraging open, trusting communication surrounding the general and gendered concerns of their female clients with FMS. This will not only facilitate a good working alliance between counselor and client, but will also implicitly model for the client a healthy, empowering, and validating relationship with a professional involved in her FMS care.

On a related note, rehabilitation counselors should ensure that their clients with FMS are receiving the health information they need to self-manage their symptoms. In the present study, FMS severity was found to be the strongest direct predictor of SWB, indicating that it is still crucial for women with FMS to manage and/or mitigate their symptoms as effectively as possible. Prior literature suggests that women with medically unexplained diagnoses often receive delayed and ineffective healthcare, as well as limited access to comprehensive sources of information regarding their illnesses, even from healthcare practitioners (Crooks & Chouinard, 2006). Providing clients with health-management resources may be an effective rehabilitation counseling intervention method; however, from a feminist perspective of disablement, this type of practice fails to address the root of the problem. In order to feel a sense of power and control over their own health, it is vital that women with FMS feel empowered and entitled to ask for these resources in healthcare settings. As noted previously, women in general are viewed as more burdensome and emotionally unstable when asserting themselves in medical spaces; compounded with the experience of having a highly stigmatized condition, one that is often and erroneously deemed to be psychosomatic in nature, women with FMS may feel especially hesitant to assert their rights to health information. This hesitancy is further complicated by the assumed social role of the medical professional as the “expert.” Furthermore, women with FMS may feel pressured to act, look, and present in certain ways to get their healthcare needs met. Werner and Malterud (2003) refer to this phenomenon as playing the “rules of the game.” These researchers found that, in order to appear credible in healthcare settings, women with medically ambiguous conditions worked extremely hard not to appear at either extreme of sick or healthy, weak or strong; rather, they exerted great amounts of effort to appear “somatically ill, whilst simultaneously avoiding appearing mentally unbalanced” (p. 1414), leaving less emotional and physical space to self-manage symptoms.

Importantly, much of the responsibility lies in medical professionals to recognize and address the problems within their own systems of healthcare (Malterud, 2000; Werner & Malterud, 2003). However, rehabilitation counselors should encourage their clients with FMS to engage in behaviors and activities that lend themselves to feelings of empowerment. For instance, women with FMS may benefit from community support groups and/or mental health counseling to find shared experience in other women with similar challenges, as well as to help manage the emotional toll of navigating disempowering spaces. Counselors should also engage in interdisciplinary work to continue bridging the gap between professionals subscribing to a medical model of disability and those advocating a biopsychosocial approach.

In keeping with the feminist framework, the present study offers a means to measure life-role participation and functioning in a way that is subjectively meaningful to the individual, as opposed to placing undue emphasis on life roles that are less significant in the individual's life. This approach is consistent with prior conceptualizations of quality of life and life satisfaction, particularly the concept of domain importance. Over the years, a number of researchers in rehabilitation and related fields have suggested that satisfaction in highly valued life areas will have a greater influence on overall QOL (Frisch, 1999; Bishop et al., 2008). Scales have also been developed to assess QOL in a way that weighs more important life areas more heavily than those that are less important (e.g. Cummins, 1997; Ferrans & Powers, 1985; Frisch, Cornell, Villanueva, & Retzlaff, 1992); however, these scales are more-so geared toward measuring QOL as a whole, as opposed to life-role participation, which is intended to serve as a predictor of SWB. Furthermore, at least two of the existing scales (Ferrans & Powers, 1985; Frisch et al., 1992) are either lengthier or more costly than the MRFQ. After further refinement and validation, the MRFQ may serve as a brief, cost-effective measure of meaningful life-role participation in both rehabilitation research and clinical practice. In the present study, meaningful role-functioning appeared to be a significant predictor of SWB. Accordingly, in assessment and treatment planning, rehabilitation counselors should encourage exploration and goal-setting surrounding improvements in functioning in the roles that hold the most importance in the client's life. Furthermore, in accordance with Super's (1980) notions surrounding life-role salience, counselors should attend to their clients' self-awareness regarding their past, current, and future life roles, how they have assigned purpose and meaning to these roles, and how their illness interacts with their most salient life roles throughout the lifespan.

Lastly, rehabilitation professionals should continue to explore illness centrality in women with chronic conditions, particularly those conditions that are relatively unpredictable in terms of their day-to-day impact on the individual's life. In the present study, illness centrality (originally called illness self-concept [ISC], but changed to aid in interpretation of results) was also a significant predictor of both meaningful role-functioning and SWB. According to Morea et al. (2008), ISC is a state-like factor, and is likely to fluctuate based on variables such as symptom severity, treatment success, coping, and social support; this suggests that illness centrality is best conceptualized through a biopsychosocial framework, whereby changes in health condition and socioenvironmental factors would influence the extent to which the individual's core self is encompassed by the illness. Future research should also explore the directionality of the relationships between illness centrality, meaningful role-functioning, and SWB. While causation cannot be determined in cross-sectional research, this model assumed that the centrality of the illness to the core self-concept would affect the individual's perception of her functioning in important life-roles, thus influencing well-being. However, it is also reasonable to assume that illness centrality could explain the relationship between meaningful role-functioning and SWB; in other words, an individual's perception of meaningful role-functioning would influence the extent to which the illness is central or peripheral to the core self.

Conclusions

Overall, the present study provided strong support for a biopsychosocial framework encompassing the medical environment, FMS severity, illness centrality, and meaningful role-functioning to predict SWB in women with FMS. As a feminist framework, the primary research model needs further refinement, as the key feminist variables added little variance to the overall model. The existing feminist research surrounding women with chronic illness and disability tend to be qualitative in nature, indicating that this particular research topic may be better geared toward qualitative methods until the development of more comprehensive and relevant quantitative measures. Future research is necessary to explain the complex relationships between the biopsychosocial factors influencing SWB in women with FMS.

References

Albrecht, G. L. (1992). *The disability business: Rehabilitation in America*. Newbury Park, CA: Sage.

Alloway, L.H. (1999). Fibromyalgia Syndrome: Symptoms, functional limitations, and vocational impediments. *Journal of Applied Rehabilitation Counseling*, 30(2), 38-41.

Ambrose, K. R., Gracely, R. H., & Glass, J. M. (2012). Fibromyalgia dyscognition: concepts and issues. *Reumatismo, 64*(4), 206.

Andrist, L. C. (1997). Integrating feminist theory and women's studies into the women's health nursing curriculum: Special topics in women's health. *Women's Health Issues*, *7*(2), 76-83.

Aparicio, V. A., Ortega, F., Carbonell-Baeza, A., Cuevas, A., Delgado-Fernandez, M., & Ruiz, J. (2013). Anxiety, depression, and fibromyalgia pain and severity. *Behavioral Psychology-Psicologia Conductual, 21*(2), 381-392.

Åsbring, P., & Närvänen, A. L. (2002). Womens' experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, *12*, 148-160.

Armitage, K. J., Schneiderman, L. J., & Bass, R. A. (1979). Response of physicians to medical complaints in men and women. *Journal of the American Medical Association, 241*(20), 2186.

Arnold, L.M., Crofford, L.J., Mease, P.J., Burgess, S.M., Palmer, S.C., Abetz,L., & Martin, S.A. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counseling, 73*, 114-120.

Asch, S.E. (1952). Social psychology. Englewood Cliffs, NJ: Prentice-Hall.

Bailey, D. E., Jr., Landerman, L., Barroso, J., Bixby, P., Mishel, M. H., Muir, A. J., . . . Clipp, E.

(2009). Uncertainty, symptoms, and quality of life in persons with chronic hepatitis C. *Psychosomatics, 50,* 138–146. doi:10.1176/appi.psy.50.2.138

Baker, G. A., Jacoby, A., Smith, D. F., Dewey, M. E., & Chadwick, D. W. (1994). Development of a Novel Scale to Assess Life Fulfilment as Part of the Further Refinement of a Quality‐of‐Life Model for Epilepsy. *Epilepsia*, *35*(3), 591-596.

Banks, M. E. (2010). 2009 Division 35 presidential address: Feminist psychology and women with disabilities: An emerging alliance. *Psychology of Women Quarterly*, *34*(4), 431-442.

Bellini, J. & Rumrill, P. (2002). Contemporary insights in philosophy of science: Implications for rehabilitation research. *Rehabilitation Education, 16*, 115-134.

Bennett, D.A. (2001). How can I deal with missing data in my study? *Australian and New Zealand Journal of Public Health, 25*(5), 464–469.

Bennett, R.M., Friend, R., Jones, K.D., Ward, R., Han, B.K., & Ross, R.L. (2009). The Revised Fibromyalgia Impact Questionnaire (FIQR): Validation and psychometric properties. *Arthritis Research and Therapy, 11*(4), 415-428.

Bennett, J. K., Fuertes, J. N., Keitel, M., & Phillips, R. (2011). The role of patient attachment and working alliance on patient adherence, satisfaction, and health-related quality of life in lupus treatment. *Patient Education and Counseling, 85*(1), 53-59. doi:http://dx.doi.org/10.1016/j.pec.2010.08.005

Bernstein, B., & Kane, R. (1981). Physicians' attitudes toward female patients. *Medical care, 19*(6), 600-608.

Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability: Preliminary analysis of a conceptual and theoretical synthesis. *Rehabilitation Counseling Bulletin*, 48, 219-31.

Bishop, M., Chapin, M.H., & Miller, S. (2008). Quality of life assessment in the measurement of rehabilitation outcome. *Journal of Rehabilitation, 74*(2), 45-54.

Bishop, M., & Feist-Price, S. (2001). Quality of life in rehabilitation counseling: Making the philosophical practical. *Rehabilitation Education*, *15*, 210–212.

Bordin, E. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research, and Practice, 16,* 252-260.

Bronstein, P. (2001). In J. Worell (Ed.), *Encyclopedia of women and gender: Sex similarities and differences and the impact of society on gender* (Vol. 1, pp. 798-808). San Diego, CA: Academic Press.

Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. In K.A. Bollen & J.S. Long (Eds.), *Testing structural equation models* (pp. 136–162). Newbury Park, CA: Sage.

Bubolz, M. M., Eicher, J. B., Evers, S. J., & Sontag, M. S. (1980). A human ecological approach to quality of life: Conceptual framework and results of a preliminary study. *Social Indicators Research*, *7*(1-4), 103-136.

Burke, P.J. (1991). Identity processes and social stress. *American sociological review*, 56, 836-849.

Burke, A. L. J., Mathias, J. L. and Denson, L. A. (2015), Psychological functioning of people living with chronic pain: A meta-analytic review. *British Journal of Clinical Psychology, 54*, 345–360. doi: 10.1111/bjc.12078

Burckhardt, C.S., Clark, B.D., & Bennett R.M. (1991). The fibromyalgia impact questionnaire: development and validation. *Journal of Rheumatology, 18,* 728-733.

Byrne, B.M. (2010). *Structural equation modeling with AMOS: Basic concepts, applications,* *and programming* (2^{nd} Ed.). New York, NY: Taylor and Francis Group.

Campos, R., & Vázquez, M. (2012). Health-related quality of life in women with fibromyalgia: clinical and psychological factors associated. *Journal of the International League of Associations for Rheumatology, 31*(2), 347-355. doi: 10.1007/s10067-011-1870-7

Cancian, F.M. (1987). *Love in America: Gender and self-development*. Cambridge, MA: Cambridge University Press.

Catalano, D., Kim, J. H., Ditchman, N. M., Shin, H. U., Lee, J., & Chan, F. (2010). The Sense of Well-Being Inventory as a quality of life measure for people with spinal cord injury. *Australian Journal of Rehabilitation Counselling, 16,* 57-72.

Chan, F., Chronister, J.A., & Cardoso, E. (2009a). An introduction to an evidence-based practice approach to psychosocial interventions for people with chronic illness and disability. In F. Chan, E. Cardoso, & J.A. Chronister (Eds.). *Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation* (pp. 3-19). New York: Springer.

Chan, F., Lee, G., Lee, E.J., Allen, C., & Kubota, C. (2007). Structural equation modeling in rehabilitation counseling research. *Rehabilitation Counseling Bulletin*, *51*, 44-57.

Chan, F., Gelman, J.S., Ditchman, N., Kim, J-H., & Chiu, C-Y. (2009c) The World Health Organization ICF model as a conceptual framework for disability. In: F. Chan, E. Cardoso, & J.A. Chronister (Eds.), *Understanding psychosocial adjustment to chronic illness and disability: A handbook for evidenced-based practitioners in rehabilitation* (pp. 23-50). New York, NY: Springer.

Chan, F., Tarvydas, V., Blalock, K., Strauser, D., & Atkins, B (2009b). Unifying and elevating rehabilitation counseling through model-drive, culturally-sensitive evidenced-based practice. *Rehabilitation Counseling Bulletin*, *52*, 114-19

Chang, F-H., Wang, Y-H., Jang, Y., & Wang, C-W. (2012). Factors associated with quality of life among people with spinal cord injury: Application of the International Classification of Functioning, Disability and Health model. *Archives of Physical Medicine and Rehabilitation, 93*, 2264-70.

Chapin, M., Miller, S.M., Ferrin, J.M., Chan, F., & Rubin, S.E. (2004). Psychometric validation of a SWB measure for people with spinal cord injuries. *Disability and Rehabilitation*, *26*, 1135-42

Chiaramonte, G.R., & Friend, R. (2006). Medical students' and residents' gender bias in the diagnosis, treatment, and interpretation of coronary heart disease symptoms. *Health Psychology, 25*, 255 – 266.

Christler, J.C. (2008). How can feminist therapists support women with autoimmune disorders? *Women and Therapy*, 23(1), 7-22.

Chronister, J. A., Johnson, E. K., & Berven, N. L. (2006). Measuring social support in rehabilitation. *Disability & Rehabilitation*, *28*, 75-84.

Chronister, J., Johnson, E., & Lin, C. P. (2009). Coping and rehabilitation: Theory, research and measurement. In F. Chan, E. Cardoso, & J. Chronister (Eds.), *Psychosocial interventions for people with chronic illness and disability: A handbook for evidence-based rehabilitation health professionals* (pp. 111-148). New York: Springer.

Cogan, R., Cogan, D., Waltz, W., & McCue, M. (1987). Effects of laughter and relaxation on discomfort thresholds. *Journal of Behavioral Medicine, 10*, 139-144.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ:

Lawrence Earlbaum Associates.

Cohen, S., Gottlieb, B. H., & Underwood, L. G. (2000). Social relationships and health. In S. Cohen, B.H. Gottlieb, & L.G. Underwood (Eds.), *Social support measurement and intervention: A guide for health and social scientists.* Oxford: Oxford University Press.

Collings, J. A. (1990). Psychosocial Well‐Being and Epilepsy: An Empirical Study. *Epilepsia, 31(4),* 418-426.

Cronbach, L.J., & Meehl, P.E. (1955). Construct validity in psychological tests. *Psychological Bulletin, 52*(4), 281-301.

Crooks, V.A., & Chouinard, V. (2006). An embodied geography of disablement: Chronically ill women's struggles for enabling places in spaces of health care and daily life. *Health and Place*, *12*, 345-352.

Cummins, R.A. (1997). *Comprehensive Quality of Life Scale – Adult (5th ed.-ComQoL-A-5).* Melbourne, Australia: Deakin University School of Psychology.

Dennis, N. L., Larkin, M., & Derbyshire, S. W. G. (2013). 'A giant mess'—Making sense of complexity in the accounts of people with fibromyalgia. *British Journal of Health Psychology, 18*(4), 763-781. doi: 10.1111/bjhp.12020

Diener, E., Emmons, R.A., Larsen, R.J., Griffin, S. (1985). The Satisfaction with Life Scale. Journal of Personality Assessment, *49*, 71–75.

Diener, E., Eunkook, S., & Oishi, S. (1997). Recent findings on SWB. *Indian Journal of Clinical Psychology, 24*, 25–41.

Doyal L and Gough I (1991) *A Theory of Need*. London: Macmillan.

Dunn, D., Elliott, T. (2008). The place of theory in rehabilitation psychology research. *Rehabilitation Psychology*, 53, 254-267.

Eberst, R. M. (1984), Defining Health: A Multidimensional Model. *Journal of School Health,* *54*, 99–104. doi: 10.1111/j.1746-1561.1984.tb08780.x

Einstein, G., & Shildrick, M. (2009). The postconventional body: Retheorising women's health. *Social Science & Medicine*, *69*(2), 293-300.

Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision making and motivational interviewing: achieving patient-centered care across the spectrum of health care problems. *The Annals of Family Medicine*, *12*(3), 270-275.

Engel, G.L. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*, 129-136.

Epstein, R. M., & Street, R. L. (2011). The values and value of patient-centered care. *The Annals of Family Medicine*, *9*(2), 100-103.

Erevelles, N. & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary and Cultural Disability Studies*, *4*(2), 127-146.

Evans, J. D. (1996). *Straightforward statistics for the behavioral sciences*. Pacific Grove, CA: Brooks/Cole.

Fabian, E.S. (1991) Using quality of life indicators in rehabilitation program evaluation. *Rehabilitation Counseling Bulletin, 34*, 344–56.

Ferrans, L.E., & Powers, M.J. (1985). Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science, 8*(1), 15-24.

Ferri, B.A. & Gregg, N. (1998). Women with disabilities: Missing voices. *Women's Studies International Forum*, *21*(4), 429-439.

Fine, M., & Asch, A. (1988). Introduction: Beyond pedestals. In M. Fine & A. Asch (Eds.).

Women with disabilities: Essays in psychology, culture, and politics (pp. 1-37). Philadelphia, PA: Temple University Press.

Folkman, S. & Moskowitz, J. T. (2004). Coping: pitfalls and promise. *Annual Review of Psychology*, 55, 745- 774.

Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology, 51,* 115-134. doi: 10.1037/0022-0167.51.1.115

Frisch, M.B. (1999). Quality of life assessment/intervention and the Quality of Life Inventory (QOLI). In M.R. Maruish (Ed.), *The use of psychological testing for treatment planning and outcome assessment* (2nd ed., pp. 1227-1331). Hillsdale, NJ: Lawrence Erlbaum.

Frisch, M.B., Cornell, J., Villanueva, M., & Retzlaff, P.J. (1992). Clinical validation of the Quality of Life Inventory: A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment, 4*, 92-101.

Fuertes, J.N., Boylan, L.S., & Fontanella, J.A. (2008). Behavioral indices in medical care outcome: The working alliance, adherence, and related factors. *Journal of General Internal Medicine, 24*(1), 80-85.

Fuertes, J.N., Mislowak, A., Bennett, J., Paul, L., Gilber, T.C., Fontan, G., Boylan, L.S. (2007). The physician-patient working alliance. *Patient Education and Counseling, 66*, 29-36.

Giesecke, T., Gracely, R.H., Grant, M.A.B., Nachemson, A., Petzke, F…& Clauw, D.J. (2004). Evidence of augmented central pain processing in idiopathic chronic low back pain. *Arthritis and Rheumatism*, *50*, 613-623. doi: 10.1002/art.20063

Goffman E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall

Gormsen, L., Rosenberg, R., Bach, F. W., & Jensen, T. S. (2010). Depression, anxiety, health-related quality of life and pain in patients with chronic fibromyalgia and neuropathic pain. *European Journal of Pain, 14,* 121-128.

Hahn, H. (1993). Political implications of disability definitions and data. *Journal of Disability and Policy Studies*, *4*(2), 41-52.

Hammel, J., Magasi, S., Heinemann, A.W., Whiteneck, G., Bogner, J., & Rodrigeuz, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, *30*(19), 1445-1460.

Harris, S., Morley, S., & Barton, S. B. (2003). Role loss and emotional adjustment in chronic pain. *Pain, 105*(1-2), 363-370. doi: 10.1016/S0304-3959(03)00251-3

Hays R.D., Sherbourne, C.D., & Mazel, R.M. (1993). The RAND 36-item health survey. *Health Economics*, *2*(3), 217-227.

Hays, R. D., & Stewart, A. L. (1992). Sleep measures. In A. L. Stewart & J. E. Ware (eds.), *Measuring functioning and well-being: The Medical Outcomes Study Approach* (pp. 235-259), Durham, NC: Duke University Press.

Heinemann, A.W., Tulsky, D., Dijkers, M., Brown, M., Magasi, S., Gordon, W., & DeMark, H. (2010). Issues in participation measurement in research and clinical applications. *Archives of Physical Medicine and Rehabilitation, 9*1, S72-S76.

Horvath, A.O., & Symonds, D. (1991). Relation between working alliance and outcome in Psychotherapy: A Meta-analysis. *Journal of Counseling Psychology, 28*(2), 139-249.

Hoth, K. F., Wamboldt, F. S., Strand, M., Ford, D. W., Sandhaus, R. A., Strange, C., . . . Holm, K. E. (2013). Prospective impact of illness uncertainty on outcomes in chronic lung disease. *Health Psychology, 32*(11), 1170-1174. doi: 10.1037/a0032721

Howard, K., Mayer, T., Neblett, R., Perez, Y., Cohen, H., & Gatchel, R. (2010). Fibromyalgia Syndrome in Chronic Disabling Occupational Musculoskeletal Disorders Prevalence, Risk Factors, and Posttreatment Outcomes. *Journal of Occupational and Environmental Medicine, 52*(12), 1186-1191. doi: 10.1097/JOM.0b013e3181fc838d

Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling*, *6*(1), 1-55. doi:10.1080/10705519909540118

Huber, J.G., Sillick, J., & Skarakis-Doyle E. (2010). Personal perception and personal factors: incorporating health-related quality of life into the International Classification of Functioning, Disability and Health. *Disability and Rehabilitation, 32*, 1955-65

Hurst, R. (2003). The international disability rights movement and the ICF. *Disability & Rehabilitation, 2003, Vol.25(11-12), p.572-576, 25*(11-12), 572-576. doi: 10.1080/0963828031000137072

Institute of Medicine (2010). Women’s health research: progress, pitfalls, and promise. Retrieved from http://www.iom.edu/Reports/2010/Womens-Health-Research-Progress-Pitfalls-and-Promise.aspx

Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D.T., Scott, R. (1984). *Social stigma: The psychology of marked relationships*. New York: Freeman

Judge, T. A., Erez, A., Bono, J. E., & Thoresen, C. J. (2003). The Core Self-Evaluations Scale (CSES): Development of a measure. *Personnel Psychology*, *56*, 303-331.

Judge, T. A., Thoresen, C. J., Pucik, V., & Welbourne, T. M. (1999). Managerial coping with organizational change: a dispositional perspective. Journal of Applied Psychology, 84, 107–122.

Judge, T. A., Van Vianen, A. E. M., & De Pater, I. E. (2004). Emotional stability, core self-evaluations, and job outcomes: a review of the evidence and an agenda for future research. Human Performance, 17, 327–347.

Julien, N., Goffaux, P., Arsenault, P., & Marchand, S. (2005). Widespread pain in fibromyalgia is related to a deficit of endogenous pain inhibition. *Pain*, *114*, 295-302.

Kammeyer-Mueller, J. D., Judge, T. A., & Scott, B. A. (2009). The role of core self-evaluations in the coping process. *Journal of Applied Psychology, 94,* 177–195. http://dx.doi.org/10.1037/a0013214

Kline, R. B. (2011). *Principles and practice of structural equation modeling* (3rd ed.). New York, NY US: Guilford Press.

Kroenke, K., Spitzer, R. L. and Williams, J. W. (2001), The PHQ-9. *Journal of General Internal Medicine, 16*: 606–613. doi: 10.1046/j.1525-1497.2001.016009606.x

Kool, M.B., & Geenan, R. (2012). Loneliness in patients with rheumatic diseases: The significance of invalidation and lack of social support. *The Journal of Psychology, 146*(1-2), 229-241.

Kool, M. B., van Middendorp, H., Lumley, M. A., Bijlsma, J., & Geenen, R. (2012). Social support and invalidation by others contribute uniquely to the understanding of physical and mental health of patients with rheumatic diseases. *Journal of Health Psychology, 18*(1), 86-95. doi: 10.1177/1359105312436438

Krupinski, J. (1980). Health and quality of life. *Social Science & Medicine. Part A: Medical Psychology & Medical Sociology*, *14*(3), 203-211.

Kurtze, N., Gundersen, K.T., & Svebak, S. (1998). The role of anxiety and depression in fatigue and patterns of pain among subgroups of fibromyalgia patients. *British Journal of*

Medical Psychology, 71, 185-94.

Laidmäe, V., Leppik, L., Tulva, T., & Hääl, M. (2009). Disease-related social and family life: People coping with rheumatoid arthritis in Estonia. *Critical Public Health*, *19*, 87–105.

Lewin, K. (1951). Field theory in social science. Chicago: Harper & Row.

Lilleaas, U.B. (1995). Na(r forskjellen blir synlig—kvinner med kroniske muskelsmerter i et kj^nnsrolleperspektiv. [When the difference becomes visible—women with chronic muscular pain in a gender-role perspective.] Working paper 8, University of Oslo, Norway: Centre for Women's Studies and Gender Research.

Link B.G., & Phelan J.C. (1999). Labeling and stigma. In *The Handbook of the Sociology of Mental Health*, C.S. Aneshensel, & J.C. Phelan (Eds.). New York: Plenum

Malterud, K. (2000). Symptoms as a source of medical knowledge: Understanding medically unexplained disorders in women. *Family Medicine, 32*(9), 603–611.

Mannerkorpi, K. & Ekdahl, C. (1997). Assessment of functional limitation and disability in patients with fibromyalgia. *Scandinavian Journal of Rheumatology*, 26, 4-13.

Marcus, D.A. (2008). Fibromyalgia: Diagnosis and treatment options. *Gender Medicine*, 6, 139-51. doi: 10.1016/j/genm/2009/01/004

Martz, E., Bodner, T., & Livneh, H. (2010). Social support and coping as moderators of perceived disability and posttraumatic stress levels among Vietnam theater veterans. *Health, 2*(4), 332-341.

Mason, M.G. (2004). *Working against odds: Stories of disabled women's work lives*. Boston, MA: Northeastern University Press.

Miller, J. (2000). *Coping with Chronic Illness: Overcoming Powerlessness, 3rd Edition*. FA Davis Co.: Philadelphia, PA.

Miller, J.B. (1976). *Toward a new psychology of women*. Boston: Beacon Press.

Miró, E., Martínez, M. P., Sánchez, A. I., Prados, G., & Medina, A. (2011). When is pain related to emotional distress and daily functioning in fibromyalgia syndrome? The mediating roles of self-efficacy and sleep quality. *British Journal of Health Psychology*, *16*, 799-814.

Molnar, D.S., Flett, G.L., Sadava, S.W., Colautti, J. (2012). Perfectionism and health functioning in women with fibromyalgia. *Journal of Psychosomatic Research*, 75, 293-300.

Montoya, P., Larbig, W., Braun, C., Preissl, H., & Burbaumer, N. (2004). Influence of social support and emotional context on pain processing and magnetic brain responses in fibromyalgia. *Arthritis and Rheumatism, 50*(12), 4035–4044

Morea, J., Friend, R., & Bennett, R. M. (2008). Conceptualizing and Measuring Illness Self-Concept: A Comparison With Self-Esteem and Optimism in Predicting Fibromyalgia Adjustment. *Res. Nurs. Health, 31*(6), 563-575. doi: 10.1002/nur.20294

Mpofu, E., Beck, R., & Weinrach, S.G. (2004). Multicultural rehabilitation counseling: challenges and strategies. In Chan, F., Berven, N.L., and Thomas, K.R. (Eds.), *Counseling theories and techniques for rehabilitation health professionals* (386-402). New York, NY: Springer.

Nettleton, S. (2006). 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms. *Social Science & Medicine, 62*(5), 1167-1178.

Oliver, M. (1990) The Politics of Disablement. Critical texts in Social Work and the Welfare State. England: Macmillan.

Peterson, D.B. (2005). International Classification of Functioning, Disability and Health: An introduction for rehabilitation psychologists. *Rehabilitation Psychology, 2*, 105-112

Piccolo, R.F., Judge, T.A., Takahashi, K., Watanabe, N., & Locke, E.A. (2005). Core self-evaluations in Japan: relative effects on job satisfaction, life satisfaction, and happiness. *Journal of Organizational Behavior, 26,* 965-984.

Pierce, G. R., Sarason, I. G., & Sarason, B. R. (1996). Coping and social support. In In M. Zeidner, N.S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 434-451). New York: Wiley.

Post, M.W., van Leeuwen, C.M., van Koppenhagen, C.F., & de Groot S (2012). Validity of the Life Satisfaction Questions, the Life Satisfaction Questionnaire, and the Satisfaction with Life Scale in persons with spinal cord injury. Archives of Physical Medicine and Rehabilitation, 93, 1832-1837

Ptacek, J. T., & Pierce, G. R. (2003). Issues in the study of stress and coping in rehabilitation settings. *Rehabilitation Psychology, 48*, 113–124.

Purdie-Vaughns, V., & Eibach, R. (2008). Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex Roles: A Journal of Research, 59*(5), 377-391. doi: 10.1007/s11199-008-9424-4

Quintana, S. M., & Maxwell, S. E. (1999). Implications of recent developments in structural equation modeling for counseling psychology. *Counseling Psychologist, 27,* 485–527.

Reed, P. (2005). Chronic pain stigma: Development of the Chronic Pain Stigma Scale (Doctoral dissertation). Retrieved from ProQuest Information and Learning Company.

Reverby, S. M. (2002). Feminism & health. *Health and History*, 5-19.

Reynolds, April. "Patient-centered care." *Radiologic Technology* 81.2 (2009): 133-147.

Roessler, R. T. (1990). A quality of life perspective on rehabilitation counseling. *Rehabilitation Counseling Bulletin*, *34*, 82–90.

Rokach, A., Lechcier-Kimel, R., & Safarov, A. (2006). Loneliness of people with physical disabilities. *Social Behavior and Personality*, *34*, 681–699.

Rubin, S. E., Chan, F., Bishop, M., & Miller, S. (2003). Psychometric validation of the Sense of Well-Being Inventory for program evaluation in rehabilitation. *Professional Rehabilitation, 11,* 54-59.

Sansone, R. A., Levengood, J., & Sellbom, M. (2004). Psychological aspects of fibromyalgia: Research versus clinician impressions. *Journal of Psychosomatic Research, 56*, 185-188.

Saunders, J.A., Morrow-Howell, N., Spitznagel, E., Doré, P., Proctor, E.K., & Pescarino, R. (2006). Imputing missing data: A comparison of methods for social work research. *Social Work Research*, 30(1), 19-31.

Schaevitz, M.H. (1984). *The superwoman syndrome.* New York: Warner Books.

Schafer J.L. (1999). Multiple imputation: a primer. *Statistical Methods in Medicine, 8*(1), 3–15. doi: 10.1191/096228099671525676.

Schneidert, M., Hurst, R., Miller, J., & Üstün, B. (2003). The role of Environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation, 25(*11-12), 588-595.

Schuster, J., McCormack, J., Riddell, R. P., & Toplak, M. E. (2009). Understanding the psychosocial profile of women with fibromyalgia syndrome. *Pain Research & Management : The Journal of the Canadian Pain Society*, *14*(3), 239–245.

Shaw, L. R., Chan, F., & McMahon, B. T. (2012). Intersectionality and disability harassment: The interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin, 55*(2), 82-91. doi: 10.1177/0034355211431167

Skuladottir , H., & Halldorsdottir , S. (2008). Women in chronic pain: Sense of control and encounters with health professionals. *Qualitative Health Research, 18*(7), 891-901.

Smart, J. F., & Smart, D. W. (2006). Models of Disability: Implications for the Counseling Profession. *Journal of Counseling & Development, 84*(1), 29-40. doi: 10.1002/j.1556-6678.2006.tb00377.x

Smedema, S.M., Catalano, D., & Ebener, D.J. (2010) The relationship of coping, self-worth, and SWB: A structural equation model. *Rehabilitation Counseling Bulletin*, 53, 131-42.

Smedema, S.M. (2014). Core self-evaluations and well-being in persons with disabilities. *Rehabilitation Psychology, 59*(4), 407-414.

Smedema, S. M., Cardoso, E., Chan, F., Dutta, A., Muller, V., Keegan, J….& Yaghmaian, R. A. (in press). The relationship of core self-evaluations and life satisfaction In individuals with disabilities: Evaluation of a mediator model. *Journal of Postsecondary Education and Disability*

Smedema, S.M., Chan, J.Y., & Phillips, B.N. (2014). Core self-evaluations and Snyder's Hope Theory in persons with spinal cord injuries. *Rehabilitation Psychology, 59*(4), 399-406.

Smedema, S. M., Pfaller, J. S., Yaghmaian, R.A., Weaver, H., Cardoso, E., & Chan, F. (2015). Core self-evaluations as a mediator between functional disability and life satisfaction in college students with disabilities. *Rehabilitation Research, Policy, and Education, 29*(1), 96-104.

Smedema, S.M. & Tansey, T.N. (2014). Mediators of the relationship between core self-evaluations and life satisfaction in individuals with spinal cord injuries. *Rehabilitation Counseling Bulletin*, 1-10. Retrieved from http://rcb.sagepub.com/content/early/2014/10/23/0034355214554608.refs

Smith, H.S. (2009). Fibromyalgia syndrome: Review of the epidemiology and mechanisms involved. *Advanced Student Medicine, 9*(4), 108-114.

Smith, H. S., Harris, R., & Clauw, D. (2011). Fibromyalgia: an afferent processing disorder leading to a complex pain generalized syndrome. *Pain physician, 14*(2), E217.

Staud, R., Vierck, C. J., Cannon, R. L., Mauderli, A. P., & Price, D. D. (2001). Abnormal sensitization and temporal summation of second pain (wind-up) in patients with fibromyalgia syndrome. *Pain*, *91*, 165-175.

Super, D. E. (1980). A life-span, life-space approach to career development. *Journal of Vocational Behavior, 13*, 282–298.

Super, D. E. (1990). A life-span, life-space approach to career development. In D. Brown, L. Brooks & Associates (eds.), *Career choice and development: Applying contemporary theories to practice* (3rd ed., pp. 121-178). San Francisco, CA: Jossey-Bass.

Super, D.E., Savickas, M.L., & Super, C.M. (1996). The life-span, life-space approach to careers. In D. Brown, L. Brooks & Associates (eds.), *Career choice and development: Applying contemporary theories to practice* (2nd ed., pp. 197–261). San Francisco, CA: Jossey-Bass.

Sutanto, B., Singh-Grewal, D., McNeil, H. P., O'Neill, S., Craig, J. C., Jones, J., & Tong, A. (2013). Experiences and Perspectives of Adults Living With Systemic Lupus Erythematosus: Thematic Synthesis of Qualitative Studies. *Arthritis Care & Research, 65*(11), 1752-1765. doi: 10.1002/acr.22032

Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed.). Boston, MA: Allyn & Bacon/Pearson Education.

Thoits, P.A. (1991). On merging identity theory and stress research. *Social Psychology Quarterly*, 54, 101-112.

Thoits, P.A. (1992). Identity structures and psychological well-being: Gender and marital status comparisons. *Social Psychology Quarterly, 55*(3), 236-256.

Tomarken, A.J., & Walker, N.G. (2005). Structural equation modeling: strengths, limitations, and misconceptions. *Annual Review of Clinical Psychology*, 1, 31-65.

Torres, X., Bailles, E., Valdes, G., Peri, J.M., Arias, A., Gomez, E., Collado, A., (2013). Personality does not distinguish people with fibromyalgia but identifies subgroups of patients. *General Hospital Psychiatry, 35*(6), 640-648.

Tracey, T.J., & Kokotovic, A.M. (1989). Factor structure of the working alliance inventory. *Psychological Assessment*, 1, 207–210.

Tsaousis, I., Nikolaou, I., Serdaris, N., & Judge, T. (2007). Do the core self-evaluations moderate the relationship between SWB and physical and psychological health? *Personality and Individual Differences*, *42*(8), 1441-1452.

Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: What is it and what is it for? *Disability and Rehabilitation*, 25, 596–601.

Ustün, T.B., Chatterji, S., Kostanjsek, N., Rehm, J., Kennedy, C., Epping-Jordan, J., … Pull C. (2011). Developing the World Health Organization Disability Assessment Schedule 2.0. B *World Health Organization, 88*, 815-23.

Üstün, T., Chatterji, S., Kastenjsek, N., Schneider, M., & Bickenbach, J. (2003). The international classification of function, disability, and health: A new tool for understanding disability and health. *Disability and Rehabilitation: An International Multidisciplinary Journal*, 25, 565-571.

van Houdenhove, B. (2003). Fibromyalgia: a challenge for modern medicine. *Clinical Rheumatology, 22*, 1-5.

van Houdenhove, B., Neerinckx, E., Onghena, P., Lysens, R., & Vertommen, H. (2001). Premorbid “overactive” lifestyle in chronic fatigue syndrome and fibromyalgia: an etiological factor or proof of good citizenship? *Journal of Psychosomatic Research, 51,* 571-576.

van Koulil, S. Lankveld, W., Kraaimaat, F.W., van Riel, P.L.C.M., & Evers, A.W.M. (2010). Risk factors for longer term psychological distress in well-functioning fibromyalgia patients: A prospective study into prognostic factors. *Patient Education and Counseling*, 80, 126-129.

Viala-Danten, M., Martin, S., Guillemin, I., & Hays, R. D. (2008). Evaluation of the reliability and validity of the Medical Outcomes Study sleep scale in patients with painful diabetic peripheral neuropathy during an international clinical trial. *Health and Quality of Life Outcomes*, *6*, 113. doi:10.1186/1477-7525-6-113

Wampold, B.E. (2000). Outcomes of individual counseling and psychotherapy: empirical evidence addressing two fundamental questions. In S.D. Brown, & R.W. Lent (Eds.). *Handbook of counseling psychology, 3rd ed.* (pp. 711-739). New York, NY: Wiley.

Ware, J.E., Kosinski ,M., Keller, S.D. (1996). A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. *Medical Care,* 34, 220 –233.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology, 54*(6), 1063-1070. doi:10.1037/0022-3514.54.6.1063

Wendell, S. (1996). The rejected body: Feminist philosophical reflections on disability. New York: Routledge.

Wendell, S. (2006). Toward a feminist theory of disability. In L.J. Davis (Ed.), *The Disability*

Studies Reader (pp. 243-256). New York, NY: Taylor and Francis Group, LLC.

Werner, A., Isaksen, L. W., & Malterud, K. (2004). ‘I am not the kind of woman who complains of everything’: Illness stories on self and shame in women with chronic pain. *Social Science & Medicine, 59*(5), 1035-1045.

Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Soc. Sci. Med., 57*(8), 1409-1419. doi: 10.1016/S0277-9536(02)00520-8

Weston, R., Gore Jr., P.A., Chan, F., Catalano, D. (2008). An introduction to using structural equation models in rehabilitation psychology. *Rehabilitation Psychology, 53*(3), 340-356.

White, M. T., Lemkau, J. P., & Clasen, M. (2001). Fibromyalgia: A feminist biopsychosocial perspective. *Women & Therapy, 23*(1), 45-58. doi: 10.1300/J015v23n01_04

World Health Organization (2001). International classification of functioning, disability and health, ICF. Geneva: World Health Organization.

Wright, B.A. (1960). Physical disability: A psychological approach. New York: Harper & Row.

Wright, B.A. (1983). Physical disability: A psychosocial approach. New York: Harper & Row.

Wright, B.A. (1972) Value-laden beliefs and principles for rehabilitation psychology. *Rehabilitation Psychology, 19*, 38–45.

Wynia, K., Middel, B., De Ruiter, H., Van Dijk, J.P., Lok, W.S., DeKeyser, J.H.A., & Reinjneveld, S.A. (2009). Adding a subjective dimension to an ICF-based disability measure for people with multiple sclerosis: development and use of a measure for perception of disabilities. *Disability and Rehabilitation, 31*, 1008-17.

Zautra, A.J., Hamilton, N.A., & Burke, H.M. (1999). Comparison of stress responses in women with two types of chronic pain: Fibromyalgia and osteoarthritis. Cognitive Therapy and

Research, 23, 209-230.

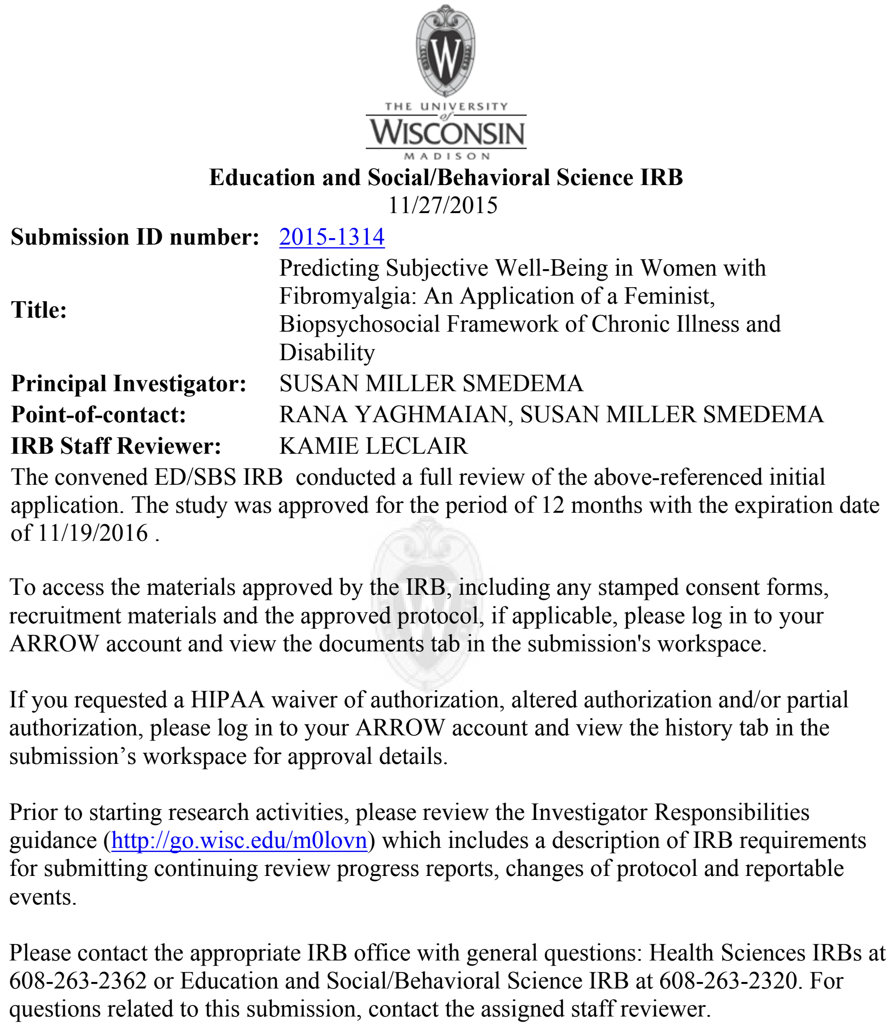
Zautra, A.J., & Manne, S.L. (1987). Coping with rheumatoid arthritis: A review of a decade of research. *Annals of Behavioral Medicine, 14*, 31-39.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, *52*, 30-41.

Zuchowski, J. (2011). *Comparing access: Health care structures and women with chronic pain illness in the united states and the united kingdom* (Order No. 3463334). Available from ProQuest Dissertations & Theses Global. (878892489).

APPENDIX A

INSTITUTIONAL REVIEW BOARD NOTICE OF APPROVAL



Education and Social/Behavioral Science IRB
11/27/2015

Submission ID number: 2015-1314
Title: Predicting Subjective Well-Being in Women with Fibromyalgia: An Application of a Feminist, Biopsychosocial Framework of Chronic Illness and Disability
Principal Investigator: SUSAN MILLER SMEDEMA
Point-of-contact: RANA YAGHMAIAN, SUSAN MILLER SMEDEMA
IRB Staff Reviewer: KAMIE LECLAIR

The convened ED/SBS IRB conducted a full review of the above-referenced initial application. The study was approved for the period of 12 months with the expiration date of 11/19/2016 .

To access the materials approved by the IRB, including any stamped consent forms, recruitment materials and the approved protocol, if applicable, please log in to your ARROW account and view the documents tab in the submission's workspace.

If you requested a HIPAA waiver of authorization, altered authorization and/or partial authorization, please log in to your ARROW account and view the history tab in the submission’s workspace for approval details.

Prior to starting research activities, please review the Investigator Responsibilities guidance (http://go.wisc.edu/m0lovn) which includes a description of IRB requirements for submitting continuing review progress reports, changes of protocol and reportable events.

Please contact the appropriate IRB office with general questions: Health Sciences IRBs at 608-263-2362 or Education and Social/Behavioral Science IRB at 608-263-2320. For questions related to this submission, contact the assigned staff reviewer.

APPENDIX B

INVITATION TO PARTICIPATE IN WEB-BASED SURVEY

Researchers at the University of Wisconsin – Madison are conducting a study about the ways in which **women with fibromyalgia** view themselves, their social environments, and their relationships with others (i.e. medical providers and family). We want to understand how these factors impact their psychological well-being and satisfaction with various aspects of life.

WHO: You are eligible to participate if you are a woman between the ages of 18 and 65 who has had fibromyalgia for one year or more.

WHAT: Participation will involve 2 rounds of surveys. Survey 1 involves completing an online survey consisting of several questionnaires that will take approximately one hour to complete. Survey 2 will take place 4 weeks following the date you participate in Survey 1 and will involve taking one brief questionnaire lasting approximately 1-3 minutes.

HOW: Please go to the following website to participate:

[Survey link here]

COMPENSATAION: The first 200 participants to complete the first survey round will receive a *$15 Target Gift Card*! The first 30 participants to complete the second survey round will receive an *additional $10 gift card*!

QUESTIONS: If you have any difficulty with the link or if you would like additional information, please contact Rana Yaghmaian, M.S., CRC by email at yaghmaian@wisc.edu, or by phone at (608) 609-0804, and she will be happy to assist you.

Thank you in advance for your participation in this important study! Findings from this study will help rehabilitation and health professionals to develop effective services to support women with fibromyalgia in achieving the highest level of well-being possible.

APPENDIX C

STUDY INFORMATION AND CONSENT FORM

UNIVERSITY OF WISCONSIN-MADISON

Research Participant Information and Consent Form

Title of the Study: Predicting SWB in Woman with Fibromyalgia

Principal Investigator: Susan Miller Smedema, PhD, CRC (phone: 608-265-0845) (email: ssmedema@wisc.edu)

Student Investigator: Rana Yaghmaian, MS, CRC (phone: 608-609-0804) (email: yaghmaian@wisc.edu)

DESCRIPTION OF THE RESEARCH

You are invited to participate in a research study about the ways in which women with fibromyalgia view themselves, their social environments, and their relationships with others (such as relationships with medical providers and family). We want to understand how these factors impact their psychological well-being and satisfaction with various aspects of life.

You have been asked to participate because you are a woman between the ages of 18 and 65 who has had fibromyalgia for more than 1 year.

This research study will take place online via a provided link.

WHAT WILL MY PARTICIPATION INVOLVE?

If you decide to participate in this research you will be asked to complete two rounds of surveys. The first round involves a series of 11 questionnaires, which will ask you to evaluate different aspects of your life. You will also be asked to answer 5 open-ended questions. Your participation will last approximately 1 hour.

The second survey round will involve taking one brief questionnaire that will last approximately 1-3 minutes. After 4 weeks (28 days), the survey system will automatically contact you via email to prompt you to take this questionnaire. Your email address will never be linked directly to your responses. Your first and second survey responses will be connected via a random number assigned to your responses by the survey system, and thus, no identifying information will be used to compare your responses.

ARE THERE ANY RISKS TO ME?

The primary risk to participants is fatigue that may be experienced as a result of completing the survey. To address this risk, although you are encouraged to complete the survey in one session, you may complete the survey in several sessions, as long as you are using the same computer.

In addition, although many of the items in the survey are positively worded and address positive aspects of life, it is possible that completing the survey may highlight potentially negative aspects of your life, causing you to feel psychological distress.

Breach of confidentiality is a potential risk to subjects. Steps to protect confidentiality (i.e. collecting emails for gift cards in a separate survey not connected to your survey responses) will be used to lessen the risk of breach of confidentiality. We will ensure that any personal, sensitive, or identifiable information revealed by participants that do not pertain to the research questions will be removed from the record, including information provided by participants in open-ended responses.

ARE THERE ANY BENEFITS TO ME?

There are no direct benefits to you from participating in the study itself, however a possible benefit of participation is furthering knowledge related to women with fibromyalgia and any improvements to programs or services that may occur as a result of this study.

WHAT WILL I RECEIVE FOR PARTICIPATING?

The first 200 participants to complete the first survey will receive a $15 Target gift card. If you wish to claim a gift card, your contact information will be collected in a separate link at the end of the survey, which will not be connected to your survey responses in any way. The first 30 participants to take the second questionnaire will receive an additional $10 Target gift card upon completion. If you wish to claim this additional gift card, your contact information will be collected in a separate link at the end of the survey, which will not be connected to your survey responses in any way.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

While there will probably be publications as a result of this study, no personally identifying information will be used. Only group characteristics will be published.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask any questions about the research at any time. If you have questions about the research after completing the survey you should contact Rana Yaghmaian by phone at 608-609-0804 or by email at yaghmaian@wisc.edu.

If you are not satisfied with the response of research team, have more questions, or want to speak with someone about your rights as a research participant, you should contact the Education and Social/Behavioral Science IRB Office at 608-263-2320.

Your participation is completely voluntary. If you decide not to participate or to withdraw from the study you will not be penalized in any way. Furthermore, while you are encouraged to answer all survey questions, you may skip or decline to answer any questions you do not wish to respond to. Again, you will not be penalized in any way for skipping or declining to answer questions.

Please note that the surveys are for research purposes only and Study Team is not in a position to make referrals or recommend support services based on the your responses.

☐ By checking this box, you indicate that you understand the information provided and agree to participate in this study.

APPENDIX D

STUDY QUESTIONNAIRE

Section 1: Demographic Information

Instructions: Please check or fill in the blanks as they best describe your situation.

Personal Information:

1.	Age	Fill in age: _________
2.	Race/Ethnicity	○ Caucasian (White) ○ African American ○ Hispanic/Latino ○ Asian American or Pacific Islander ○ Native/Indian American ○ Others (Specify): __________________________
3.	Marital Status	○ Single ○ Married ○ Divorced ○ Widowed ○ Separated ○ Cohabitating
4.	Education Level	○ No formal education ○ Elementary education (Grades 1-8) ○ Secondary education, no high school diploma (Grades 9-12) ○ Special education certificate of completion/diploma or in attendance ○ High school graduate or equivalency certificate ○ Post-secondary education, no degree ○ Associate degree or vocational/technical certificate ○ Bachelor’s degree ○ Master’s degree or higher

Employment Information:

5.	Employment Status	○ Full-time employed (More than 30 hours per week) ○ Part-time employed (Less than 30 hours per week) ○ Retired ○ Student ○ Volunteer ○ Unemployed but actively looking for a job ○ Unemployed and not looking for a job ○ Unemployed but receiving vocational services
8.	Health Insurance	○ No insurance ○ Medicare ○ Medicaid ○ Public insurance from other source ○ Insurance through your own employer ○ Insurance through your spouse’s or another family member’s employer

		○ Private insurance purchased by you or other family members ○ Others (Specify): ___________________
9.	Have you ever accessed vocational rehabilitation services?	○ Yes ○ No
10.	SSA beneficiary (Mark all that apply)	○ Supplemental Security Income (SSI) ○ Social Security Disability Income (SSDI) ○ None ○ Others __________________

Fibromyalgia Information:

11.	Age at onset	Fill in age: ____________
12.	Age at diagnoses	Fill in age: ____________

Other Health Information:

15.	Any other health conditions	○ No other health conditions ○ Physical disability (e.g. you require assistance using a cane, wheelchair, or walker to walk) ○ Mental illness (e.g. depression, anxiety) ○ Arthritis ○ Chronic Fatigue Syndrome (CFS) ○ Irritable Bowel Syndrome (IBS) ○ Raynaud's Syndrome ○ Temporomandibular Joint Disorder (TMJ) Others (Specify): _________________

16. In the space below, please describe your fibromyalgia symptoms:

Section 2: FIQR

Directions: For each of the following 9 questions check the box that best indicates how much your fibromyalgia made it difficult to perform each of the following activities during the past 7 days. If you did not perform a particular activity in the last 7 days, rate the difficulty for the last time you performed the activity. If you can't perform an activity, check the last box.

1.	Brush or comb your hair	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
2.	Walk continuously for 20 minutes	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
3.	Prepare a homemade meal	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
4.	Vacuum, scrub or sweep floors	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
5.	Lift and carry a bag full of groceries	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
6.	Climb one flight of stairs	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
7.	Change bed sheets	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
8.	Sit in a chair for 45 minutes	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**
9.	Go shopping for groceries	**No difficulty**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very difficult**

Directions: For each of the following 2 questions, check the box that best describes the overall impact of your fibromyalgia over the last 7 days:

1.	Fibromyalgia prevented me from accomplishing goals for the week	**Never**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Always**
2.	I was completely overwhelmed by my fibromyalgia symptoms	**Never**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Always**

Directions: For each of the following 10 questions, select the box that best indicates your intensity of these common fibromyalgia symptoms over the past 7 days.

1.	Please rate your level of pain	**No pain**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Unbearable Pain**
2.	Please rate your level of energy	**Lots of energy**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**No energy**
3.	Please rate your level of stiffness	**No stiffness**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Severe stiffness**
4.	Please rate the quality of your sleep	**Awoke well rested**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Awoke very tired**
5.	Please rate your level of depression	**No depression**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very depressed**
6.	Please rate your level of memory problems	**Good memory**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very poor memory**
7.	Please rate your level of anxiety	**Not anxious**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very anxious**
8.	Please rate your level of tenderness to touch	**No tenderness**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Very tender**
9.	Please rate your level of balance problems	**No imbalance**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Severe imbalance**
10.	Please rate your level of sensitivity to loud noises, bright lights, odors, and cold	**No sensitivity**	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	**Extreme sensitivity**

Section 3: MSPSS

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

		Very Strongly Disagree	**Strongly Disagree**	**Mildly Disagree**	**Neutral**	**Mildly Agree**	**Strongly Agree**	**Very Strongly Agree**
1.	There is a special person who is around when I am in need	1	2	3	4	5	6	7
2.	There is a special person with whom I can share my joys and sorrows	1	2	3	4	5	6	7
3.	My friends really try to help me	1	2	3	4	5	6	7
4.	I get the emotional help and support I need from my family	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me	1	2	3	4	5	6	7
6.	My friends really try to help me	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong	1	2	3	4	5	6	7
8.	I can talk about my problems with my family	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends	1	2	3	4	5	6	7

Section 4: PPWA

Instructions: Below there are sentences that describe some of the different ways you might think or feel about your doctor (or primary health care provider). As you read the sentences below use this 7-point scale to respond to each statement. Use the numbers in between to describe the variations between these extremes. Place the number on the blank to the left of each statement. Please make sure that you answer **every item**.

		Strongly Disagree	**Disagree**	**Slightly Disagree**	**Neutral**	**Slightly Agree**	**Agree**	**Strongly Agree**
1.	My doctor and I agree about the things I need to do to help improve my health.	1	2	3	4	5	6	7
2.	My doctor gives me new ways of looking at my health.	1	2	3	4	5	6	7
3.	I believe that my doctor likes me.	1	2	3	4	5	6	7
4.	I believe that my doctor trusts me.	1	2	3	4	5	6	7
5.	I am confident in my doctor's ability to help me.	1	2	3	4	5	6	7
6.	My doctor and I agree on my treatment plan.	1	2	3	4	5	6	7
7.	My doctor understands all of what I am going through with my medical problem.	1	2	3	4	5	6	7
8.	My doctor and I agree on what is important for me to do.	1	2	3	4	5	6	7
9.	I trust my doctor.	1	2	3	4	5	6	7
10.	My doctor and I have different ideas about my medical problem(s).	1	2	3	4	5	6	7
11.	We established a good understanding of the kind of changes that would be good for me.	1	2	3	4	5	6	7
12.	I believe that the way we are working to solve my medical problem(s) is correct.	1	2	3	4	5	6	7

Section 5: CPSS

Instructions: Each of the following statements describes attitudes that some people may express about chronic pain. Read each statement carefully. Then check the response that best fits how you feel about the statement. Do not think too much about your answers; just circle the first response that feels right to you.

Please note: In the following 10 statements, the word **PEOPLE** refers to **people in general**, not to members of your family.

		Strongly Agree	**Agree**	**Somewhat Agree**	**Somewhat Disagree**	**Disagree**	**Strongly Disagree**
1.	People believe that someone with chronic pain is as mentally and emotionally healthy as the average person	1	2	3	4	5	6
2.	People believe that it is mostly the patient's fault when his/her pain does not get better	1	2	3	4	5	6
3.	People are sympathetic when they hear about my pain condition	1	2	3	4	5	6
4.	People believe that chronic pain is used as an excuse to get pain medication	1	2	3	4	5	6
5.	People understand the suffering experienced by someone with chronic pain	1	2	3	4	5	6
6.	I feel embarrassed to tell people that I cannot do something because of my pain	1	2	3	4	5	6
7.	People think less of someone who is unable to work because of chronic pain	1	2	3	4	5	6
8.	People believe that having chronic pain is a sign of personal weakness	1	2	3	4	5	6
9.	People think that someone taking prescription pain medication on a regular basis in a "drug addict"	1	2	3	4	5	6

10.	When people hear that someone has chronic pain, they think that person is also likely to have a mental or emotional problem	1	2	3	4	5	6

***Please note*:** In the following 10 statements, the word **DOCTOR** refers to **<u>all doctors you have seen for your pain,</u>** not just your current doctor.

		Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
1.	Most doctors believe that there is real physical cause for chronic pain.	1	2	3	4	5	6
2.	Doctors think that people with chronic pain exaggerate their pain.	1	2	3	4	5	6
3.	Many doctoral think that people with chronic pain want more pain medication than is necessary for their physical.	1	2	3	4	5	6
4.	Doctors think that chronic pain is mostly a mental or emotional problem.	1	2	3	4	5	6
5.	Most doctors think that people with chronic pain use pain medication appropriately.	1	2	3	4	5	6
6.	Most doctors think that people with chronic pain complain about their illness about as much as people with other medical conditions.	1	2	3	4	5	6
7.	Many doctors believe that people with chronic pain could be more physically active if they wanted.	1	2	3	4	5	6
8.	Many doctors think that people with chronic pain are less emotionally stable than people with other medical problem.	1	2	3	4	5	6
9.	Many doctors think that people with chronic pain are “drug addicts”.	1	2	3	4	5	6

10.	Most doctors would prefer not to treat people with chronic pain.	1	2	3	4	5	6

Please note: In the following 10 statements, the word **FAMILY** refers to the **<u>people who are most important and significant to you.</u>**

		Strongly Agree	**Agree**	**Somewhat Agree**	**Somewhat Disagree**	**Disagree**	**Strongly Disagree**
1.	My family understands that I have physical pain.	1	2	3	4	5	6
2.	My family thinks I need less pain medication that I take.	1	2	3	4	5	6
3.	My family feels that I exaggerate how much I hurt in order to get out of doing things that I don't want to do.	1	2	3	4	5	6
4.	My family understands that I only use as much pain medication as is medically necessary.	1	2	3	4	5	6
5.	My family thinks that I could be more physically active if I wanted.	1	2	3	4	5	6
6.	My family thinks that by taking pain medication on a regular basis, I have become a "drug addict"	1	2	3	4	5	6
7.	My family understands that chronic pain is a real medical condition.	1	2	3	4	5	6
8.	I feel that my family has less respect for me since I have developed chronic pain.	1	2	3	4	5	6
9.	My family thinks that chronic pain is more of a mental or emotional problem than a physical problem.	1	2	3	4	5	6

10.	My family feels embarrassed to tell people that I have a chronic pain condition.	1	2	3	4	5	6

Section 6: CSES

Instructions: Below are several statements about you with which you may agree or disagree. Using the response scale below, indicate your agreement or disagreement with each item by placing the appropriate number on the line preceding that item.

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
1.	I am confident I get the success I deserve in life.	1	2	3	4	5
2.	Sometimes I feel depressed.	1	2	3	4	5
3.	When I try, I generally succeed.	1	2	3	4	5
4.	Sometimes when I fail I feel worthless.	1	2	3	4	5
5.	I complete tasks successfully.	1	2	3	4	5
6.	Sometimes, I do not feel in control of my work.	1	2	3	4	5
7.	Overall, I am satisfied with myself.	1	2	3	4	5
8.	I am filled with doubts about my competence.	1	2	3	4	5
9.	I determine what will happen in my life.	1	2	3	4	5
10.	I do not feel in control of my success in my career.	1	2	3	4	5
11.	I am capable of coping with most of my problems.	1	2	3	4	5

12.	There are times when things look pretty bleak and hopeless to me.	1	2	3	4	5

Section 7: ISCS

		1 Strongly Agree	**2 Agree**	**3 Somewhat Agree**	**4 Somewhat Disagree**	**5 Disagree**	**6 Strongly Disagree**
1.	My illness is with me most of the time	1	2	3	4	5	6
2.	I am preoccupied with my illness	1	2	3	4	5	6
3.	I have a positive view of life, in spite of my illness	1	2	3	4	5	6
4.	I try not to let my illness control how I feel	1	2	3	4	5	6
5.	My illness is at the center of who I am	1	2	3	4	5	6
6.	My illness is often on my mind	1	2	3	4	5	6
7.	I do not allow my illness to affect too many parts of my life	1	2	3	4	5	6
8.	I feel consumed by my illness	1	2	3	4	5	6
9.	I only think of my illness when I have to	1	2	3	4	5	6
10.	My illness has undermined my confidence in myself and what I can do	1	2	3	4	5	6
11.	At times, it seems like my illness runs my life	1	2	3	4	5	6

12.	I have preserved my sense of self, in spite of my illness	1	2	3	4	5	6
13.	It seems like almost everything I do is influenced by my illness	1	2	3	4	5	6
14.	I do many of the same things as healthy others, despite my illness	1	2	3	4	5	6
15.	My illness has affected nearly all aspects of my life	1	2	3	4	5	6
16.	My illness prevents me from doing things I need to do	1	2	3	4	5	6
17.	I do not let my illness take over my life	1	2	3	4	5	6
18.	I am dominated by my illness	1	2	3	4	5	6
19.	My illness has NOT kept me from doing the things I enjoy doing	1	2	3	4	5	6
20.	My illness prevents me from being the kind of person that I wish to be	1	2	3	4	5	6
21.	I see myself as a healthy person, in spite of my illness	1	2	3	4	5	6
22.	I rarely feel trapped by my illness	1	2	3	4	5	6
23.	My illness dictates nearly everything I do	1	2	3	4	5	6

Section 8: MRFQ

The following questionnaire items pertain to the life roles that you identify with.

Part 1: Please rate the following items based on the extent to which you view the particular life role or life area as significant, meaningful, and valuable. ***If you do not identify with a particular role, rate yourself as 0 ("I do not identify with this role").***

		0 **I do not identify with this role**	**1** **Not at all important**	**2** **Not very important**	**3** **Neutral**	**4** **Somewhat important**	**5** **Very important**
1.	**Being a parent or caregiver**	0	1	2	3	4	5

2.	**Being a son or daughter**	0	1	2	3	4	5
3.	**Being a spouse or partner**	0	1	2	3	4	5
4.	**Being a friend**	0	1	2	3	4	5
5.	**Being a community citizen**	0	1	2	3	4	5
6.	**Participating in leisure activities**	0	1	2	3	4	5
7.	**Being a student or learner**	0	1	2	3	4	5
8.	**Having a job**	0	1	2	3	4	5
9.	**Having a social life**	0	1	2	3	4	5
10.	**Homemaking**	0	1	2	3	4	5

Part 2: Please rate the following items based on your personal evaluation of how well you function in each life role or life area. ***If you do not identify with a particular role, rate yourself as 0 ("I do not identify with this role").***

		0 I do not identify with this role	**1 Very poorly**	**2 Somewhat poorly**	**3 Neutral**	**4 Somewhat well**	**5 Very well**
1.	**Being a parent or caregiver**	0	1	2	3	4	5
2.	**Being a son or daughter**	0	1	2	3	4	5
3.	**Being a spouse or partner**	0	1	2	3	4	5
4.	**Being a friend**	0	1	2	3	4	5
5.	**Being a community citizen**	0	1	2	3	4	5
6.	**Participating in leisure activities**	0	1	2	3	4	5
7.	**Being a student or learner**	0	1	2	3	4	5
8.	**Having a job**	0	1	2	3	4	5
9.	**Having a social life**	0	1	2	3	4	5

10.	**Homemaking**	0	1	2	3	4	5

In the space below, please list any other important, significant, and/or meaningful life roles that were not included in the previous questionnaire:

In the space below, describe the ways in which your fibromyalgia affects your ability (if at all) to successfully fulfill the life roles and/or life areas that are important to you:

Section 9: WHODAS-II 36 Participation Subscale

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

		1 None	**2 Mild**	**3 Moderate**	**4 Severe**	**5 Extreme or cannot do**
1.	How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
2.	How much of a problem did you have because of barriers or hindrances in the world around you?	1	2	3	4	5
3.	How much of a problem did you have living with dignity because of the attitudes and actions of others?	1	2	3	4	5
4.	How much time did you spend on your health condition, or its consequences?	1	2	3	4	5

5.	How much have you been emotionally affected by your health condition?	1	2	3	4	5
6.	How much has your health been a drain on the financial resources of you or your family?	1	2	3	4	5
7.	How much of a problem did your family have because of your health problems?	1	2	3	4	5
8.	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	1	2	3	4	5

Section 10: PANAS

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. **Indicate the extent you have felt this way over the past week.**

		1 Very Slightly or Not at All	**2 A Little**	**3 Moderately**	**4 Quite a Bit**	**5 Extremely**
1.	Interested	1	2	3	4	5
2.	Distressed	1	2	3	4	5
3.	Excited	1	2	3	4	5
4.	Upset	1	2	3	4	5
5.	Strong	1	2	3	4	5
6.	Guilty	1	2	3	4	5
7.	Scared	1	2	3	4	5

8.	Hostile	1	2	3	4	5
9.	Enthusiastic	1	2	3	4	5
10.	Proud	1	2	3	4	5
11.	Irritable	1	2	3	4	5
12.	Alert	1	2	3	4	5
13.	Ashamed	1	2	3	4	5
14.	Inspired	1	2	3	4	5
15.	Nervous	1	2	3	4	5
16.	Determined	1	2	3	4	5
17.	Attentive	1	2	3	4	5
18.	Jittery	1	2	3	4	5
19.	Active	1	2	3	4	5
20.	Afraid	1	2	3	4	5

Section 11: SWLS

Instructions: Please indicate your agreement with each item by checking the appropriate number.

		Strongly Disagree	**Disagree**	**Slightly Disagree**	**Neither Agree nor Disagree**	**Slightly Agree**	**Agree**	**Strongly Agree**
1.	In most ways, my life is close to ideal	1	2	3	4	5	6	7
2.	The conditions of my life are excellent	1	2	3	4	5	6	7
3.	I am satisfied with my life	1	2	3	4	5	6	7
4.	So far, I have gotten the important things I want out of life	1	2	3	4	5	6	7
5.	If I could live my life over, I would change almost nothing	1	2	3	4	5	6	7

Section 12: Open-Ended Prompts

In the space below, please describe how you feel being a woman affects the way people (including the general public, family members, and medical professionals) treat you. If you do not feel being a woman affects the way people treat you, please indicate that in the space below.

In the space below, please describe how you feel being a person with fibromyalgia affects the way people (including the general public, family members, and medical professionals) treat you. If you do not feel being a person with fibromyalgia affects the way people treat you, please indicate that in the space below.