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THE RELEVANCE OF CLIENT-HEALTHCARE PROVIDER COMMUNICATION
TO THE APPRAISAL OF ILLNESS UNCERTAINTY IN WOMEN WITH
FIBROMYALGIA SYNDROME

By

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B.S.N., Bellarmine University, 1990
M.S.N., Bellarmine University, 2006

A Dissertation
Submitted to the Faculty of the
School of Nursing of the University of Louisville
In Partial Fulfillment of the Requirements
For the Degree of

Doctor of Philosophy
in Nursing

Department of Nursing
University of Louisville
Louisville, Kentucky

December 2015

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A Dissertation Approved on

November 9, 2015

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DEDICATION

I dedicate this dissertation to my father and mother, Edward and Patricia Grant.

Dad, thank you for showing me that a strong work ethic is the key to success. Mom, you are a remarkable woman. I admire how you embrace each day with strength and fortitude.

Thank you for your unconditional love.

ACKNOWLEDGEMENTS

I want to take this opportunity to thank my Dissertation Chairperson, Dr. Marianne Hutti and my fellow committee members, Drs. Lee Ridner, Mary Beth Coty, and Donna Pearson for their commitment to me. Thank you for dedicating time, sharing knowledge, and mentoring with high standards. I truly appreciate the valuable guidance each member of the committee provided over this intensive year. I am especially thankful for the numerous times Dr. Hutti and Dr. Pearson met with me to discuss my ideas and interpretations concerning my research. I am also very thankful for Dr. Tim Crawford's statistical assistance and willingness to meet with me to discuss moderated mediation. It is my opinion that Dr. Crawford has the patience of a Saint. To my colleagues at Bellarmine University, thank you for your flexibility and reminding me to not lose sight of my goals.

I extend my deepest gratitude to my husband, Michael. Thank you for your love, encouragement, and faith in me. The journey was long and very stressful at times. However, you empowered me and facilitated my success. I look forward to pursuing new adventures with you and vow to support your artistic career. I also want to acknowledge and thank my three daughters, Victoria, Olivia, and Julia for their abundance of warm hugs, understanding, and encouraging words. Julia, I will be forever grateful for the countless times you stepped in and assumed the role of "mom" for Joshua while I worked on my dissertation. Lastly, but very importantly, thank you Joshua for giving our family new perspective on life.

ABSTRACT

THE RELEVANCE OF CLIENT-HEALTHCARE PROVIDER COMMUNICATION TO THE APPRAISAL OF ILLNESS UNCERTAINTY IN WOMEN WITH FIBROMYALGIA

Melody Reibel

November 9, 2015

Illness uncertainty and impaired client-healthcare provider (HCP) communication are critical healthcare problems for women with fibromyalgia syndrome (FMS). However, the relationship between illness uncertainty and client-HCP communication has not been previously examined. The purposes of this dissertation were to (a) gain a deeper understanding of the lived experiences of women with FMS, (b) to examine the relationships among client-HCP communication, illness uncertainty, helplessness, and subjective well-being (SWB) in women with FMS, and (c) evaluate the psychometric properties of the patient-HCP communication scale (PHCPCS) in women with FMS.

A mixed-methods design enhanced validity of the findings. The qualitative pilot study showed that multiple factors contributed to the anguish experienced by the sample of women living with FMS. Participants' narratives revealed illness uncertainty was a salient experience and that client-HCP interactions influenced the women's uncertainty.

The results of the quantitative study revealed a statistically significant relationship between illness uncertainty and SWB. However, the results of the mediation testing demonstrated the effects of uncertainty on the participant's SWB were indirect and

mediated through helplessness. The overall regression model explained 46% of the variance in SWB.

There was a lack of empirical evidence to support the posited moderating effect of client-HCP communication on the relationships between illness uncertainty and helplessness, and helplessness and SWB. Inconsistencies found between the samples' mean score on the PHCPCS and the narrative communication data indicated future research is needed to evaluate the content validity of the PHCPCS in women with FMS.

The qualitative findings provide support for the theoretical work of Mishel (1990) and contribute to the literature by increasing understanding of the lived experiences of women with FMS. In addition, the data suggest that while illness uncertainty is associated with emotional distress in women with FMS, it is the individual's perceived sense of helplessness that strongly influences the impact of illness uncertainty on SWB.

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CHAPTER I

INTRODUCTION

Fibromyalgia syndrome (FMS) is a chronic, multifaceted illness that causes widespread, profound musculoskeletal pain. Fibromyalgia has been coined a “syndrome” due to the multiple symptoms that co-exist with the chronic pain state. Altered sensory function, extreme fatigue, stiffness, non-restorative sleep, anxiety, depression, migraines, difficulty with cognition, and gastrointestinal disorders are commonly experienced by individuals with FMS (Wolfe et al., 1990; Wolfe et al., 2010). FMS exists worldwide in all socioeconomic classes and ethnic groups and affects approximately 10 million adults in the United States (US). The incidence of FMS is highest in women over age 50, and is two to seven times more likely to affect females versus males (National Fibromyalgia and Chronic Pain Association [NFMCPA], 2014; Weir et al., 2006).

Accumulating evidence indicates FMS is a critical healthcare problem. The relentless, diffuse pain and multiple co-morbidities experienced with FMS encumber quality of life (QOL), affecting physical and mental well-being (Annemans, Lay, & Taieb, 2009; Egeli, Crooks, Matheson, Ursa, & Marchant, 2008; Geisser et al., 2008; Lempp, Hatch, Carville, & Choy, 2009; Schleicher et al., 2005; Shuster, McCormack, Ridell, & Toplack, 2009). Chronic pain, anxiety, and depression are the most common disabling symptoms of FMS (Schafer et al., 2011). The prevalence of depression in individuals with FMS ranges from 20% to 86% with a documented median of 58%

(Grob, 2011; Maurel et al., 2011; Shuster et al., 2009). Furthermore, FMS has a severe impact on ability to engage in activities of daily living. Researchers have found middle-aged women in the US with FMS experience more difficulty with physical functioning than an average 80-89 year old female (Jones, Rutledge, Jones, Matallana, & Rooks, 2008).

Further indication for FMS as a significant healthcare challenge is evidenced by its detrimental impact on work productivity (Annemans et al., 2009; Phillips & Stuijbergen, 2010). Since 1992, with the World Health Organization's (WHO) inception of FMS as a medical diagnosis, there has been a steady increase in the number of disability claims (Grob, 2011; World Health Organization [WHO], 2015). A study conducted by Schaefer et al. (2011) examined the impact of FMS on individual's work productivity in the United States. The researchers found that 38% of the participants who were unemployed indicated they were disabled because of FMS. In the same study, the employed participants reported missing an average of 23 days of work per year because of FMS. Additionally, the National Fibromyalgia Association (NFA) (2014) reported overall healthcare costs for FMS clients are twice as high as other insurance claimants. The estimated treatment expense incurred by an individual with FMS is \$5,310 per year.

Statistical evidence indicates FMS has imposed a significant economic burden on society due to decreased work productivity and high costs that result from the amount of sick leave, unemployment, and treatment expense associated with FMS (Annemans et al., 2009; Grob, 2011; Schaefer et al., 2011). In addition, researchers have reported participants' descriptions of how FMS has impacted their quality of life. Multiple studies have revealed the inability of individuals to meet self-expectations, rely on their bodies to

perform as they did prior to FMS, maintain their professional occupation, and participate in daily activities with family and friends (Dow, Roche, & Ziebland, 2012; Egeli et al., 2008; Franks, Cronan, & Oliver, 2004; Lempp et al., 2009). Furthermore, findings indicate that lack of support from healthcare professionals has contributed to the humanistic burden experienced by women with FMS. In addition to living with multiple debilitating symptoms, women with FMS face a diagnosis that has been viewed with skepticism by the healthcare community (Hayes et al., 2010; Lempp et al., 2009; Schaefer, 2005; Thorne et al., 2004; Briones-Vozmediano, Vives-Cases, Ronda-Perez, & Gil-Gonz, 2013).

FMS is an ambiguous illness (Gard & Deodhar, 2012). The symptoms experienced with FMS remit and exacerbate; the degree of pain severity and its precise location is unpredictable (Wierwille, 2012). There is no known cure for FMS and controversy within the healthcare profession concerning the exact cause of fibromyalgia's complex, variable symptoms can be traced back to the 16th century (Inanici & Yunus, 2004). Over the past two decades, research efforts have focused on unraveling the mystery concerning the pathophysiology of FMS. While diffuse pain and stiffness in muscles and joints are noted as defining symptoms, FMS differs from arthritic conditions in that the pain experienced with FMS is not a result of joint inflammation or tissue damage (Spaeth & Briley, 2009). Although the exact etiology remains unknown, the preponderance of the literature indicates the pathogenesis of FMS is rooted in the neurological system. Hypersensitivity of central nervous system neurons, malfunction of pain pathways, and atypical hormone responses have been proposed as probable causes for the amplified pain experience (Abeles, Pillinger, Solitar, & Abeles, 2007). Despite

these scientific advances, the validity of FMS has remained a source of debate among healthcare providers (HCPs) (Fitzcharles, Ste-Marie, & Pereira, 2013; Grob, 2011; Wolfe, 2009).

The skepticism concerning FMS is compounded by the lack of clear diagnostic standards. There are no biomarkers for diagnosis of FMS (Boomershine, 2011; Garg & Deodhar, 2012). Although the American College of Rheumatology (ACR) has established classification criteria for FMS, the criteria are based on subjective findings and have received much criticism (Wolfe, 2009; Wolfe et al., 2010). It is estimated that HCPs' reliance on the 1990 ACR FMS classification criteria as a diagnostic tool has contributed to the misdiagnosis of 46% of FMS clients (Katz, Wolfe, & Michaud, 2006).

Given the nebulous symptoms of FMS and the long history of contention concerning its diagnostic validity, it is not surprising that one of the salient experiences of women living with FMS includes illness uncertainty (Johnson, Zautra, & Davis, 2006). Nursing theorist, Mishel first defined illness uncertainty as a cognitive state in which the individual is unable to determine the meaning of an illness related-event and foresee precise outcomes (Mishel, 1988). Later, Mishel (1990) reconceptualized uncertainty in illness by delineating uncertainty in the context of chronic illness. The theorist emphasized that uncertainty in chronic illness is often perceived as a contagious force that infiltrates all aspects of daily living, alienating its sufferers from their familiar lifestyle. According to Mishel, the ongoing disruption of lifestyle experienced with chronic illness often precipitates a state of unrelenting chaos in which there is perceived loss of control over life circumstances. Consequently, the experienced turmoil acts as a

catalyst generating further uncertainty in the individual's life (Mishel, 1990; Mishel, 1999).

The FMS qualitative literature provides support for Mishel's (1990) conceptual definition of uncertainty in chronic illness. Qualitative studies have shown the diagnosis of fibromyalgia perpetuates a client's illness uncertainty (Madden & Sim, 2006; Mengshoel & Heggen, 2004; Lempp et al., 2009; Egeli et al., 2008). Madden and Sim (2006) found participants experienced an initial sense of relief after receiving a long awaited fibromyalgia diagnosis. However, because FMS was poorly understood and often equated with absence of organic disease, a diagnosis of FMS failed to provide a socially valid explanation for the women's symptoms and thus contributed to their experiences of uncertainty.

Theory and research indicate that communication between clients and their HCPs influences illness uncertainty in women with FMS. Mishel's (1990) reconceptualized uncertainty in illness theory (RUIT) identifies a HCP's provision of information as an antecedent to uncertainty and an influential component in the appraisal of uncertainty. Specifically, a HCP's communication concerning the realm of diagnosis, treatment options, and expected client outcomes are important contextual cues that assist with the appraisal of illness uncertainty (Mishel, 1990).

Phenomenological studies of individuals living with FMS revealed the individual's level of illness uncertainty was exacerbated by negative communication interactions with HCPs. A HCP's unwillingness to listen to the individual's healthcare concerns, discuss alternative treatments outside of pain medication, complete disability forms, and provide referrals with providers from other healthcare disciplines were

identified as contributors to illness uncertainty in persons with FMS (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Shuster et al., 2009). Participants in qualitative studies have conveyed an acute awareness of the stigma associated with FMS that ensues from HCPs, as well from their family members, friends, and co-workers. This conveyance of skepticism from HCPs, family, and members of their social network stands out as a prominent theme in the qualitative literature. Participants' narratives reveal perceptions of being labeled as malingerers, lazy, crazy, and noncompliant when seeking healthcare for FMS (France, Farrell, Kearney, & Myatt, 2008; Egeli et al., 2008; Lempp et al., 2009; Schaefer, 2005; Schoofs et al., 2004).

While qualitative inquiry shows uncertainty is a prevalent problem for women with FMS, there is a paucity of quantitative research that has examined illness uncertainty in women with FMS (Anema, Johnson, Zeller, Fogg, & Zetterland, 2009; Reich, Johnson, Zautra, & Davis, 2006). Nevertheless, the limited evidence indicates that illness uncertainty is a risk factor for development of emotional disturbance in individuals with FMS (Reich et al., 2006). Researchers report illness uncertainty lowers the individual's level of self-efficacy in relation to effectively coping with the pain and multiple symptoms of FMS. Specifically, illness uncertainty was found to have a significant relationship with anxiety, depression, and negative affect (Johnson et al., 2009; Reich et al., 2006).

Mishel's (1990) RUIT provides a framework through which HCPs may understand the human response to illness uncertainty and recognize the instrumental role that client-HCP communication plays in the appraisal of illness uncertainty in women with FMS. However, a review of the qualitative literature suggests that the healthcare

community as a whole has missed the opportunity to use the knowledge from Mishel's (1990) theory to facilitate the appraisal of illness uncertainty in FMS clients and assist with their positive adaptation to chronic illness. Additionally, the lack of quantitative studies dedicated to the research area of illness uncertainty and its correlates in women with FMS indicates a critical need to evaluate the relevance of client-HCP communication to the appraisal of illness uncertainty in women with FMS. A discussion of the foundational concepts of Mishel's (1990) RUIT and the modification of Mishel's (1990) RUIT used to guide this dissertation research will be presented in the conceptual framework section of Chapter One.

The purposes of this dissertation research study were to (a) gain a deeper understanding of the lived experiences of women with FMS, (b) to examine the relationships among client-HCP communication, illness uncertainty, helplessness, and subjective well-being (SWB) in women with FMS, and (c) evaluate the psychometric properties of the patient-HCP communication scale (PHCPCS) (Salt et al., 2012) in women with FMS. The dissertation is comprised of three manuscripts. The first manuscript, presented in Chapter Two, examines the results from a qualitative pilot study that used a phenomenological approach to explore the experiences of women living with and seeking treatment for FMS. The qualitative manuscript is presented prior to the quantitative studies to facilitate the reader with a deeper understanding of the phenomena. The results from the qualitative pilot study were used to assist (a) the identification of critical variables that needed further examination in women with FMS, and (b) the development of the conceptual framework that guided the quantitative inquiry. Chapter Three describes the quantitative research findings from a cross-sectional study that

examined the relationships among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS. The third and final manuscript, presented in Chapter Four, evaluates the psychometric properties of the PHCPCS (Salt et al., 2012) in women with FMS. Lastly, Chapter Five synthesizes the research findings from all previous chapters and discusses the limitations of the research, practice implications, and the need for future research.

A mixed-methods design was chosen to strengthen the overall findings of the dissertation research. Use of both qualitative and quantitative inquiry addressed the purposes and specific aims of the research, yielded meaningful data, and enhanced validity of the research findings. Specifically, use of phenomenology in the qualitative pilot study promoted a deeper understanding of the lived experiences of women with FMS and assisted with the identification of client-HCP communication, illness uncertainty, helplessness, and SWB as important variables that needed further examination in women with FMS. The quantitative study in Chapter Three provided clarity regarding how these variables of interest related to one another and assisted with development of an evidence base to direct future practice interventions for women with FMS. The psychometric evaluation of the PHCPCS in Chapter Four yielded information concerning internal consistency reliability and dimensionality of the PHCPCS when used to measure the quality of client-HCP communication in women with FMS. Finally, synthesis of the findings from the dissertation research facilitated insight of the complexity of FMS and how the meaning ascribed to having FMS affects the appraisal of uncertainty in women with FMS. Additionally, the findings assisted with identifying gaps in knowledge and the need for future research concerning the effect of client-HCP

communication on the relationship between illness uncertainty and helplessness and between helplessness and SWB in women with FMS.

Discussion of

Philosophical Assumptions

Recognizing and respecting the individualized needs of each person is a foundational principle that underlies all nursing practice (American Nurses Association [ANA], 2015). As a registered nurse, this researcher has provided care for multiple individuals with acute and chronic illness. Thus, past experience in the healthcare profession has played an influential role in the formation of this researcher's views concerning ontology and epistemology. Ontology addresses one's belief concerning the nature of reality and epistemology refers to how knowledge is constructed (Creswell, 2013, p. 20-21).

The purpose of the qualitative pilot study in the dissertation research was to gain a deeper understanding of the lived experiences of women with FMS. The intention of the research was to gain this understanding through the meanings that were conveyed by the participants. As a nurse researcher with a strong belief in multiple realities and truths, phenomenology was chosen as the appropriate research methodology to bring forth a consciousness and deeper understanding of the human experience of living with FMS (Creswell, 2013, p. 20-21; van Manen, 1990, p. 10-11).

An essential characteristic of a qualitative researcher entails the capacity to be surprised or be open to the unexpected. To facilitate thoroughness and achieve accuracy with the qualitative inquiry in the dissertation research, increased self-awareness and identification of personal assumptions occurred prior to conducting the qualitative pilot

study. A concentrated effort to maintain a non-judgmental attitude was employed throughout the research process. The importance of bracketing personal past experiences associated with this researcher's professional role in healthcare was recognized. Although total disengagement from previous HCP experiences with women with FMS was unrealistic, emphasis was placed on suspending any pre-conceived beliefs concerning the phenomenon. Remaining vigilant during the interviewing process, residing in the moment, and actively listening to participant's stories allowed the phenomenon to speak for itself (Dahlberg, Nystrom, & Drew, 2001, p. 97-98).

Epoche, or often referred to as bracketing, was introduced by Husserl, the father of phenomenology. Epoche entails the setting aside of the researcher's personal experiences with the phenomenon to facilitate a new perspective (Creswell, 2013, p. 80; van Manen, 1990, p. 175-176). In keeping with this important concept, as a female researcher, the potential for bias in reference to the perceived needs of females was recognized. Acute awareness of this researcher's personal experiences with traditionally associated female gender roles such as mother, nurse, and educator was necessary to filter past knowledge while exploring the lived experiences of women with FMS.

Conceptual Framework: A Modification of Mishel's (1990) Reconceptualization of Uncertainty in Illness Theory (RUIT)

Description of the RUIT

The overall use of Mishel's (1988; 1990) uncertainty theories is extensive and includes studies in multiple medical populations. While more attention has been devoted to the study of uncertainty using Mishel's (1988) original uncertainty in illness theory (UIT), support for Mishel's (1990) reconceptualized uncertainty in illness theory (RUIT)

was found in qualitative studies with various chronic illnesses, including breast cancer survivors, long term diabetics, multiple sclerosis, and systemic lupus erythematosis (SLE) (Mishel, 1999; Mishel & Clayton, 2008). Few researchers have used Mishel's (1988; 1990) uncertainty theories to examine illness uncertainty in individuals with FMS. Yet, Mishel's (1990) RUIT is a useful framework for understanding how women living with FMS may cognitively process and manage uncertainty.

The RUIT is an expansion of Mishel's (1988) original UIT. The impetus for the development of the RUIT emerged from Mishel's awareness of the gaps in the original UIT in relation to addressing the experiences of chronically ill individuals (Mishel & Clayton, 2008). The central concept of uncertainty and antecedent portion of the original UIT were retained in the expanded theory; however, probabilistic thinking and subsequent formation of a new worldview were identified as pertinent outcomes for individuals with chronic illness versus the outcome of adaptation to uncertainty as described in the original UIT (Mishel & Clayton, 2008).

Mishel (1990) proposed the uncertainty experienced with chronic illness differs from the uncertainty experienced with acute illness. The uncertainty experienced with chronic illness is unrelenting and creates continual disruption in the individual's way of life. Unlike acute illness, chronic illness is often difficult to diagnose and treat and is characterized by multiple intrusive symptoms that remit and exacerbate in an unpredictable pattern. Furthermore, the illness uncertainty experienced with chronic illness often escalates to the point in which it exceeds the individual's coping threshold and leads to an unbalanced state of mind (Mishel, 1990).

A temporal component concerning the appraisal of uncertainty in chronic illness was introduced by Mishel's (1990) RUIT. The sense of chaos experienced with chronic illness often leads to an insidious process in which the appraisal of uncertainty shifts from danger to opportunity. Mishel emphasized this gradual change in the appraisal of uncertainty involves probabilistic thinking; the belief in a conditional, changing world. Additionally, the theorist posited individuals with chronic illness who progress to probabilistic thinking recognize that uncertainty is part of the natural rhythm of their life and thus abandon the finite, absolute rules traditionally held by society. This new worldview adopted by the individual with chronic illness entails the acceptance of a constant state of fluctuation and multiple alternatives in life (Mishel, 1990).

Modification of Mishel's (1990) RUIT

The conceptual framework for the quantitative study in Chapter Three consisted of a modification of Mishel's (1990) RUIT (See Figure 1). According to Mishel (1990), a HCP's provision of information to clients concerning etiology, symptoms, treatment, and trajectory of illness is an antecedent to uncertainty and a key factor that influences a client's appraisal and management of uncertainty in chronic illness. Additionally, the theorist emphasized that affectivity and personality traits affect the appraisal of uncertainty. The antecedent portion of Mishel's (1990) RUIT along with the foundational concepts of illness uncertainty in chronic illness were incorporated in the model for this dissertation.

For this study, subjective well-being (SWB) was identified as an appropriate outcome variable in place of probabilistic thinking and the attainment of a new worldview. Deiner (2000) defined SWB as an individual's self-appraisal of life based on

personal aspirations and a blend of subjective reactions to objective reality. Positive appraisal of SWB is often equated with a peaceful state of mind and satisfaction with life (Deiner, 2000; McDowell, 2010). The implicit assumption identified in Mishel's (1990) RUIT entails optimal SWB is achieved in individuals with chronic illness when probabilistic thinking occurs and uncertainty is integrated as a natural way of life.

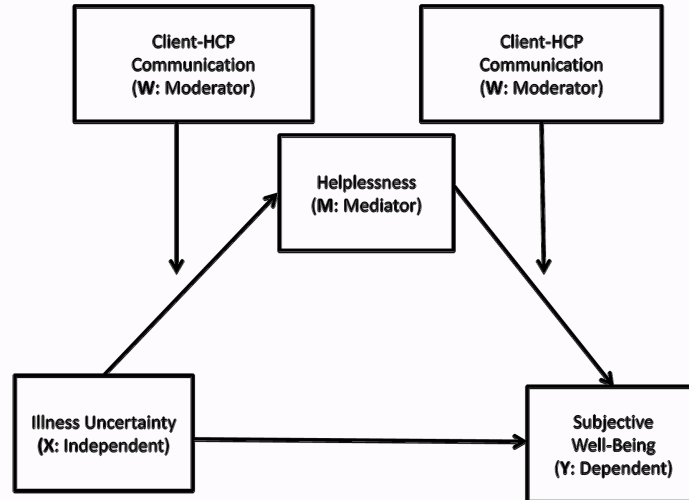


Figure 1. Modification of Mishel's (1990) Reconceptualized Theory of Uncertainty

In summary, the model for the quantitative inquiry was based on the FMS literature, findings from the qualitative pilot study in the dissertation research, and the foundational concepts of Mishel's (1990) RUIT. Client-HCP communication was proposed as an antecedent variable that would moderate the relationship between illness uncertainty and helplessness; and helplessness and SWB in women with FMS. There was specific interest in the construct, helplessness and its role in the appraisal of illness

uncertainty in women with FMS. Thus, the role of helplessness as a mediating variable between illness uncertainty and SWB in women with FMS was examined. Additionally, based on the literature concerning the nature of FMS as a chronic pain disorder, the constructs pain severity, functional status, and illness duration were identified as potential confounding variables in the model.

CHAPTER II

BEYOND THE PAIN: A LOOK INTO THE EXPERIENCES OF WOMEN LIVING WITH AND SEEKING TREATMENT FOR FIBROMYALGIA SYNDROME

Fibromyalgia Syndrome (FMS) is a mysterious chronic illness characterized by diffuse musculoskeletal pain, fatigue and a myriad of comorbidities (Wolfe, 2009; Wolfe et al., 1990; Wolfe et al., 2010). Weir et al. (2006) found individuals with FMS are two to seven times more likely than persons without FMS to have been diagnosed with depression, anxiety, migraines, gastrointestinal disorders, chronic fatigue syndrome, and autoimmune disease, such as rheumatoid arthritis (RA). Although FMS may strike children, and men and women of all ages, the incidence is highest in middle-aged females (National Fibromyalgia Association [NFA], 2015; Weir et al., 2006). Importantly, FMS imposes a substantial burden, as it causes disability and impacts quality of life (Annemans et al., 2009; Egeli et al., 2008; Lempp et al., 2009; Robinson et al., 2012; Schleicher et al., 2005; Shuster et al., 2009).

In the past two decades, chronic pain research has produced a body of literature concerning the clinical pathology of FMS. While these efforts have facilitated the healthcare profession's understanding of the physiological underpinnings of fibromyalgia, the literature consistently reveals FMS continues to be an obscure illness. Shortcomings in the diagnosis, assessment, and treatment of FMS remain, and thus pose a major healthcare challenge (Gard & Deodhar, 2012; Weirwille, 2012). Consequently,

these limitations along with the invisible symptoms experienced with FMS have resulted in an illness that is often dismissed by the medical community and society. Women living with FMS struggle with establishing credibility of their illness (Dow et al., 2012; Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004; Thorne et al, 2004).

A historical review of FMS assists with understanding the evolution of the illness over 500 years. Rhuman (as cited in Inanici & Yunus, 2004) introduced the term rheumatism in the 16th century to describe the clinical symptoms of musculoskeletal pain that accompanied rheumatic fever. In 1904, the nomenclature for musculoskeletal pain shifted to the term fibrositis. The word, fibrositis, stems from Latin and Greek origins with *fibra* meaning fiber or fibrous tissue. The suffix, *itis* was added to fibrositis due to the belief that inflammation was the primary cause of the musculoskeletal pain (Grob, 2011; Online Etymology Dictionary, 2015). However, this historical period also marked the onslaught of medical debate concerning the validity of fibrositis. Differences in physicians' opinions concerning the cause of the musculoskeletal pain ranged from functional changes in the muscle itself, to nervous system hyperactivity induced by exposure to environmental climate changes, physical exertion, or emotional disturbance (Inanici & Yunus, 2004).

In 1940, Comroe, (as cited in Grob, 2011) reported an increased prevalence of fibrositis in the American and British soldiers of World War II. This phenomenon resulted in further investigation of the clinical pathology of fibrositis. Clinical assessment of soldiers revealed depression was a prominent symptom that co-existed with the musculoskeletal pain. However, failure to link an inflammatory or degenerative process

with the muscular aches and pains led to the labeling of fibrositis as a psychogenic induced illness (Grob, 2011; Inanici & Yunus, 2004).

Traut's (1968) and Smythe's (1972) seminal research findings (as cited in Inanici & Yunus, 2004) facilitated further characterization of fibromyalgia. Traut found increased incidence of fibrositis in females versus males and emphasized the importance of the mind-body interaction in its pathogenesis. Smythe, known as the grandfather of FMS was the first to document fibrositis as a generalized pain syndrome accompanied by fatigue, insomnia, multiple tender points, and emotional distress. Additionally, for the first time in history, emphasis was placed on the role of non-restorative sleep in exacerbating the symptoms of musculoskeletal pain (Grob, 2011; Inanici & Yunus, 2004).

Research findings during the late 1970's and early 1980's were pivotal in the establishment of fibromyalgia as a syndrome. In 1976, the contemporary medical term fibromyalgia syndrome (FMS) replaced the term fibrositis (Grob, 2011; Inanici & Yunus, 2004). Fibromyalgia has Latin and Greek origins with *myos* meaning muscles, and *algos* meaning pain (Online Etymology Dictionary, 2015). Yunus, Masi, Calabro, Miller and Feigenbaum (1981) found tender points were greater in patients with fibromyalgia than control subjects and identified additional symptoms associated with fibromyalgia such as numbness, tingling, irritable bowel syndrome and migraines.

In the following decade, Wolfe (1990), a prominent fibromyalgia researcher and team of colleagues spearheaded research efforts to establish classification criteria for FMS (Grob, 2011). The 1990 American College of Rheumatology (ACR) classification criteria for FMS consists of a client's history of widespread musculoskeletal pain or

tenderness for a minimum of three months and pain in at least 11 out of 18 bodily tender points during physical examination using a specified amount of pressure (Wolfe et al., 1990). However, potential for variability in a HCP's palpation technique while performing the tender point exam is identified as a major limitation of the criteria (Boomershine, 2011).

The 1990 ACR criteria have been criticized for the deficiencies of the criteria in detecting the concomitant conditions associated with FMS (Wolfe et al., 2010). Overall, the literature suggests the 1990 ACR FMS classification criteria fail to capture the totality of the illness (Boomershine, 2011; Garg & Deodhar, 2012). Therefore, in 2010, the ACR approved revised classification criteria for FMS (Boomershine, 2011; Wolfe et al., 2010). The new criteria were developed to assist with diagnosing FMS in the primary care setting and also promote a shift in the definition of FMS from a peripheral pain disorder to a disease that is defined by systemic symptoms (Wolfe et al., 2010).

Garg and Deodhar (2012) reported the revised ACR criteria improved correct diagnostic rates of FMS in the primary care setting. Elimination of the tender point count decreased potential for examination error in the primary care setting and the addition of a scale to evaluate symptoms and monitor the course of the disease over time facilitated HCPs with assessing severity of FMS. However, limitations were noted with the revised ACR criteria. The criteria continue to lack biomarkers for diagnosing FMS and cannot be applied to clients who have additional rheumatic disorders such as, RA or systemic lupus erythematosus (SLE) (Boomershine, 2011). Overall, the literature indicates the need for further research to examine reliability and validity of the 2010 ACR FMS criteria (Boomershine, 2011; Gard & Deodhar, 2012).

Research efforts over the past 20 years have increased knowledge and awareness of fibromyalgia's clinical pathology (Wierwille, 2012). Hypersensitivity of central nervous system neurons and alteration in descending inhibitory pain pathways are identified as probable causes of the musculoskeletal pain. Fatigue, a prevalent clinical manifestation of FMS, is exacerbated by impaired oxygen supply to muscles secondary to prolonged activation of the stress response. Dysfunction of neurotransmitters, such as norepinephrine, GABA, serotonin, dopamine, glutamate, and substance P are suggested culprits of sleep disturbance and the amplified pain response (Abeles et al., 2007; National Fibromyalgia Association [NFA], 2015).

Multiple studies have identified barriers encountered by individuals as they search for a diagnosis and treatment. Difficulty in establishing therapeutic client-HCP relationships is identified as a primary problem for individuals with FMS (Annemans et al., 2009; Perrot, Choy, Petersel, Ginovker, & Kramer, 2012). Qualitative researchers have reported client's perceptions of receiving minimal HCP support, lack in continuity of care, being misunderstood, and often misdiagnosed by members of the medical community (Briones-Vozmediano et al., 2013; Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009). Furthermore, evidence in the literature of the detrimental impact on quality of life (QOL), affecting physical, psychological, and social factors, clearly establishes FMS as a contemporary healthcare challenge for women (Anema et al., 2009; Cranford & King, 2011; Egeli et al., 2008; Lempp et al., 2009).

While scientific advances provide support for its pathologic causes, FMS remains a controversial condition. The "fibromyalgia wars" continue between HCPs concerning etiology and management of FMS, among pharmaceutical companies concerning the

most effective medication, and within the government agencies concerning disability compensation for patients. In the balance of the ongoing battles, clients with FMS struggle to obtain credibility for their symptoms and illness (Wolfe, 2009).

The literature points to a critical need to improve the healthcare professions' understanding of women's experiences with client-HCP relationships. The purpose of this qualitative pilot study was to gain a deeper understanding of the experiences of women living with and seeking treatment for FMS. The intention of the research was to gain this understanding through the meanings that were conveyed by the women with FMS. Thus, a phenomenological approach was used to obtain rich descriptions from the participants to uncover, and gain insight of the lived experiences of women with FMS.

Methodology

Phenomenology encompasses multiple definitions. German philosopher, Heidegger (1962) (as cited in van Manen, 1990, p. 12) described phenomenology as a mindful wondering about what it means to live a life. Phenomenology is a human science that asks the question, "what is this experience like?" (van Manen, 1990, p. 9-11 & 181). As a philosophy, phenomenology is a way of viewing the world (Creswell, 2013, p. 24). Heidegger contended human experience is contextual, based on the individual's worldview. Thus, a main philosophical underpinning of phenomenology consists of the belief that subjective meanings of experiences are formed as a result of social interactions in the world (Lavery, 2003). Importantly, phenomenology is a methodology that brings forth a consciousness and deeper understanding of the lived human experience (Creswell, 2013, p. 20-21; van Manen, 1990, p. 10-11).

The practice of hermeneutic phenomenology involves awareness of the descriptive aspect of its methodology and engagement in the interpretation of the phenomenon (van Manen, 1990, p.180). The word hermeneutic stems from the Greek verb, *hermeneuein*, which means to interpret (Online Etymology Dictionary, 2015). Heidegger (as cited in Lavery, 2003) posited the interpretation that occurs with hermeneutic phenomenology is a circular, repetitive process in which the researcher goes back and forth to the participant's text or to the world to discover new and meaningful interpretations.

van Manen's (1990) phenomenological method of reflection and writing was a primary source in guiding this study. Once the participants were selected for interview, the research included (a) maintaining a concerted focus on the phenomenon while investigating the life-world experience of women with FMS; (b) listening to the recorded interviews and reflecting on the women's stories to grasp the essential meaning of the lived experience with FMS; (c) transcribing the narratives verbatim and reviewing the text for accuracy; (d) thematically analyzing the text and allowing the phenomenon to unfold; and (e) validation of the themes and assurance of the trustworthiness of the data (van Manen, 1990).

Focus on the Phenomenon

Phenomenology as a methodology allows us to research lived experience so that we might better understand a phenomenon in our own lives and in the lives of others. The uniqueness of phenomenological research entails its ability to differentiate between a description of an event and its essence. Thus, phenomenology is a reflective process.

Phenomenology clarifies the obscurity of an experience by revealing its underlying structure so others will grasp the experience and its significance (van Manen, 1990, p.32).

The practice of thoughtfulness in phenomenological research entails a deep commitment to focusing on the phenomenon (van Manen, 1990, p. 31). To achieve this state of mindfulness, a researcher must first examine personal assumptions and suspend pre-conceived beliefs concerning the phenomenon (Note researcher assumptions in Chapter One). Importantly, the research was approached with “openness” to allow the phenomenon to unfold and speak for itself (Dahlberg, Nystrom, & Drew, 2001, p. 97-98).

Interviews and Reflection Process

Phenomenological interviews were conducted with three women who were purposefully selected from a fibromyalgia support group in the southern region of the United States. The interviews were conducted by the first author of the current study in each of the women’s own homes. Following informed consent, the women were invited to share their experiences of living with FMS. The interviews began with the open-ended question, ‘*What was your experience in seeking healthcare for your Fibromyalgia?*’ As the participants shared their stories of living with FMS, their accounts were reflected upon and subsequent questions were asked during the interview to gain further insight of their experiences. The interviews were audio-recorded with permission of the participants. Additionally, a journal kept by this researcher concerning observations and self-reflections facilitated a continual orientation to the phenomenon (Creswell, 2013, p. 166-167; van Manen, 1990, p. 32-33).

Transcription and Review of the Text

This researcher, the first author, listened to the recorded interviews several times to appreciate the women's verbal intonations. Next, the recordings were transcribed verbatim and the transcripts were read thoroughly in order to capture the nature of the women's lived experiences. This comprehensive reading approach was used to recognize the overarching significance of the text as a "whole" (van Manen, 1990, p. 33 & 93). van Manen emphasized qualitative researchers need to balance the research context and evaluate how each of the "parts" of the experience contributes to the "whole" of the experience.

Thematic Analysis

Following the comprehensive review of the text, the transcriptions were analyzed and coded. A collaborative dialogue between the primary author and an advising researcher facilitated the qualitative analytic process (van Manen, 1990, p. 100). A structural description of "how" the experience happened was written initially and then followed by a textural description of "what" the women in the study experienced. The writings of both descriptions in conjunction with the "wholistic" reading approach facilitated with uncovering the essences of the women's lived experiences with FMS (Creswell, 2013, p. 193-195; van Manen, 1990, p. 92-95).

According to van Manen (1990, p. 92) a vast array of data sources that describe lived experience may be used to assist with the interpretation of the text and facilitate conveying the meaning of the phenomenon to the world. These sources may include excerpts from diaries, film, drama, poetry, and novels. This unique approach was used to facilitate understanding of the lived experiences of women with FMS. Artistic expressions were extracted from classic literary sources and from fibromyalgia support

group webpages to provide an implicit expression of the themes and thus assist with illuminating the women's experiences. One of the participants shared with this researcher that persons with FMS often use the reflective writing process to express their personal experiences with FMS.

Validation of Themes

Johnson and Christensen (2012) described several strategies to maximize validity of qualitative research. The following strategies were used to ensure trustworthiness of the data, (a) reflexivity, (b) theory triangulation, (c) peer review, and (d) participant feedback.

Reflexivity, the process of self-reflection, is a critical strategy for qualitative researchers (Johnson & Christensen, 2012). This researcher engaged in self-reflection to increase awareness of personal assumptions and potential biases in the research. Theory triangulation involved a literature review to assist with the interpretation of the participants' experiences. In addition, the experiences of the participants provided support for Mishel's (1990) reconceptualized uncertainty in illness theory (RUIT).

Multiple peer review sessions between this researcher and the advising researcher were also used to ensure trustworthiness of the data. During these sessions, the researchers discussed their interpretations and posed challenging questions to facilitate solid evidence for their interpretations and conclusions. Lastly, this researcher conducted a member check with each participant to solicit their views of the interpretation and credibility of the findings. All three women in the study were provided an opportunity to confirm, clarify, and to respond to the themes and the textual expressions used to convey the meaning of their experiences.

Findings

Pseudonyms were used for the women whose narratives revealed the nature and meaning of their common lived experience with FMS. The following themes emerged as *Kay*, *Sara*, and *Mary* shared their experiences in living with and seeking treatment for fibromyalgia: “There is Nothing We Can Do for You,” “We’ve Got to Find Something,” “I Feel like I’m Going Crazy,” “Losing,” “My Best Day,” and “Hope: I Can Do This”.

“There is Nothing We Can Do for You”

Over the years there has been controversy in the medical community regarding the legitimacy of fibromyalgia as a chronic illness. The prevalence of psychological comorbidities that accompany fibromyalgia, unclear etiology, lack of objective diagnostic criteria, and lack of physician’s understanding of fibromyalgia are the main contributing factors to HCPs’ skepticism (Perrot et al., 2012).

Each of the women began their stories with a reflection of their quest in the healthcare system. The women described a long and arduous journey of searching for a HCP to diagnose and provide treatment for their illness. Among these women, the experience of living with fibromyalgia was one of being dismissed by the medical community. It was and continues to be an experience laced with disappointment and accompanied by a range of emotions from anxiety, frustration and fear to outright anger.

Kay’s journey with fibromyalgia began seven years ago. Kay’s symptoms of fatigue and pain have interfered with her ability to care for her grandchild and perform daily household functions. At her first visit to her physician, Kay struggled for the words to describe the characteristics of her pain:

It was about seven years ago. I had a primary doctor and I kept telling him I didn’t feel right.... I just didn’t feel right at all...I hurt, my skin was

crawling and I just... didn't feel...right. So, he (primary physician) goes, "well...we could check into it, you know...uh, you might have chronic pain or it just might be fibromyalgia." I said, "well,.. what is that?" He said, "it involves the nerves and he said I may be having symptoms of that." So, I said, "is there anything you can do to find out?" (Primary physician reply) "No, there is no test for it," ...and I said,... "OK."

The appointment ended abruptly as she heard her physician say, "no, there is no test for it." Entrusting in her physician's word and medical expertise, Kay left the appointment with an "OK," and without any clear answers to what was causing her pain or how to manage the pain.

Sara is a young woman who began her fight with fibromyalgia early in life and has spent years searching for a diagnosis and treatment from multiple HCPs. Sara described a similar experience in the early stages of her journey:

He (rheumatologist) pretty much looked at me and said, "OK"... and then he went through this list of medications, and I said... "I've been on that, ...I've been on that, ...that doesn't work for me, ...that put me in the hospital",...and then he just looked at me and said,... "there is NOTHING I can do for you. If I can't prescribe you medication, there is NOTHING I can do for you." I just started crying in the room. I couldn't take it anymore.

Her experience was one of dismissal and hopelessness. As she left her HCP's office she was at once confronted by the reality that her pain level, distress, and state of daily existence may never improve. There was nothing they could do for her.

Mary was diagnosed with fibromyalgia in the peak of her professional career. As the severity of her illness increased, Mary was faced with the possibility that she could no longer perform at her workplace. She first assumed her symptoms of pain and exhausting fatigue were caused from pushing herself to perform at work. As her symptoms began to spiral out of control, Mary began her quest for answers. She described the experience this way:

The neurosurgeon was the one that diagnosed me with fibromyalgia. His exact words were in fact, "Up to today, unfortunately, (he started laughing), I am not going to make any money off of you,but what I'm going to tell you, ...you might not be familiar with, ...but I would like you to Google it and get more information. You have fibromyalgia."

For Mary, hearing the laughter of her physician was a devastating moment, one that provoked fear. It was a fear of the unknown during the early stages of seeking help. Apprehension continued to resurface as each of the women spoke of their experiences in living with FMS.

The raw descriptions from each of these women concerning their initial interactions with the medical community are often difficult to comprehend. When individuals seek healthcare, they anticipate having an interaction with a HCP who will convey empathy and genuine concern while meeting their healthcare needs. They expect to leave with increased clarity on ways to manage their illness and relieve their distress (Charlton, Dearing, Berry, & Johnson, 2008; Thorne et al., 2004). For these women, the search for answers was far removed from that expectation.

The experiences of Kay, Sara, and Mary were reminiscent of Lewis Carroll's book (1865) *Alice's Adventures in Wonderland* as the character Alice searched for her destination. Alice tumbles down the "rabbit hole" without any idea of how she will find her way out of Wonderland.

Alice: Would you tell me, please, which way I ought to go from here?
The Cheshire Cat: That depends a good deal on where you want to get to.
Alice: I don't much care where.
The Cheshire Cat: Then it doesn't much matter which way you go.
Alice: ...So long as I get SOMEWHERE.
The Cheshire Cat: Oh, you're sure to do that, if only you walk long enough.
(Carroll, 1865, p. 39-40).

Like these women, Alice's conversation with the Cheshire Cat was filled with ambiguous responses and left her confused with no path to follow.

“We've Got to Find Something”

Women with FMS spend a significant amount of time searching for answers and treatment in the healthcare system. The literature indicates clients with FMS have visited between three to six HCPs prior to receiving a diagnosis (Annemans et al., 2009). Further indication for FMS as a critical health problem is found in the exponential use of health resources. National annual healthcare costs for FMS range from 12 to 14 billion per year (National Fibromyalgia and Chronic Pain Association [NFCPA], 2014).

Pharmacological treatment is one of the more common treatments offered by HCPs. Studies have shown 81.5% of individuals with FMS report the use of prescription drugs to relieve symptoms and 52% of those individuals using prescription drugs perceive minimal relief (Greenson et al., 2008; Hardy-Pickering, Adams, Sim, Roe, & Wallymahamed, 2007). All three women in this study described with anguish the pursuit of an answer and the pacification that inevitably ensued primarily through prescriptions. Their words revealed the magnitude of fibromyalgia as a multidimensional illness—an illness affecting not only the physical body, but also the mind and virtually all domains of their lives. With courage, each pursued an answer.

A month had passed between Kay's first and second encounter with her HCP. During this time her experience of living with fibromyalgia had been one of dysfunction. The fatigue and pain had increased to the point that she felt her body “was going to burst.” Depressed and filled with defeat she persisted in finding an answer:

Well, after my body kept getting worse, and it affected my work, it just got to the point I couldn't function. I was depressed real bad. I went back to

him (primary physician) and I said, “we’ve got to find something.” He said, “Well... maybe we should put you on Xanax,” and I said, “that’s not taking care of the problem.”

Kay had garnered the courage to return to her physician a second time and she asked her HCP “to find something” to explain her pain and distress. Instead what Kay received was an attempt to mollify her with a prescription of Xanax.

Sara endured multiple and sometimes repetitive tests “just so they could find something.” Her narrative revealed the experience of pacification of a different kind than Kay. Sara elaborated on a second visit from a different HCP for her FMS. During this visit, Sara’s physician questioned her about a support group bracelet she was wearing.

The rheumatologist that I saw knew what fibromyalgia was... but he didn’t believe in it. When he saw the support group bracelet on my arm, he said, “Where did you get this?” I said, “from the fibromyalgia support group.” I said, “I have found other people like me, this is real... I don’t care what you say.” From here on out I found another doctor.

Not only were these women mollified with prescriptions, like Sara, they also endured a subtle form of chastisement for seeking solutions beyond the drugs. Similar to Kay and Sara, Mary continued her search for answers from the medical community with the hope of improving the quality of her life. However, Mary’s experience with a specialist was one of pacification that left her and her husband in a state of uncertainty and fear, as she explained:

I went to see a rheumatologist and the first thing she did was talk to me for five minutes,.... and then she wrote a prescription for Lyrica,.... and I went home. I looked up the medication and read about it, and we...were so scared.

In the above quote, Mary expressed her fear of taking the medication, Lyrica. Lyrica, or sometimes called by its generic name, pregabalin, is marketed by the pharmaceutical company Pfizer. It became the first United States Food and Drug

Administration (FDA) approved drug for FMS, and therefore is a common drug prescribed by HCPs to relieve the widespread neuropathic pain experienced by individuals with FMS (American Hospital Formulary Services, 2013). However, adverse effects associated with Lyrica have been documented. The FDA medication guide (2013) lists life threatening allergic reactions, suicidal thoughts or actions, swelling of the hands and feet, dizziness, and increased sleepiness as potential side effects of Lyrica.

The impact of FMS on each of the women's mental state became evident as the interview progressed. Their narratives revealed an underlying fear of spiraling down into an emotional state that would impair their ability to cope with the manifestations of FMS. Two of the three women in this study, specifically mentioned having suicidal thoughts.

My depression and mood swings would become pretty severe. I would get to the point when I couldn't do it anymore. There were several times my husband and my psychiatrist would be extremely worried, ... (Mary's voice softened)because I was suicidal....I got to the point where I couldn't do it anymore.

Depression is highlighted as one of the most prevalent co-morbidities of FMS with a documented range of 20% to 86% and a median of 58% (Grob, 2011; Maurel et al., 2011; Shuster et al., 2009). The following excerpt from a poem written by a "Fibro-Fighter" helps us to understand the power of chronic pain and how it infiltrates the mind. In the poem we hear the fear culminate as a result of the unknown, an escalating state of anxiety, and chronic unrelieved pain.

You have made me cry. You have made me scream.
You have made me think the unthinkable.....
You will not go away. You are my constant companion
(Surviving Chronic Pain- Sheryl, Facebook, 2013)

"I Feel Like I'm Going Crazy"

"The tests show you are fine, these are the words that are said,

-you are imagining it,.... its all in your head.”
(Fibrothoughts- Swanson, 2010-2013)

Individuals living with chronic illness have increased awareness of the negative stigma that society often associates with chronic pain (Telford, Kralik, & Koch, 2006). HCPs, family members, friends, and colleagues often assign the labels of crazy, lazy, hypochondriac, noncompliant, or drug seeker to individuals with FMS. Furthermore, stigmatized health identity is compounded by HCPs’ constant questioning concerning the legitimacy of clients’ symptoms (Annemans et al., 2009; Shuster et al., 2009).

Living in a society in which we must “see” in order to believe, it is much easier for people to comprehend the suffering of an individual when there are outward signs and symptoms (Mishel, 1990; 1999). Women with FMS present with symptoms that are complex and not necessarily visible to the naked eye; they struggle with convincing HCPs, friends, colleagues, and even family members to believe their symptoms are real (Lempp et al., 2009; Schaefer, 2005).

Each of the women in this study openly shared feelings that they were “going crazy” as they searched for a diagnosis and treatment for symptoms of fibromyalgia: Kay, Sara, and Mary’s narratives revealed a kind of invisibility that magnified the stigmatization from others and eventually contributed to self-doubt. The following passages elucidate what they experienced:

It was awful, I felt like I was going crazy. My husband would say, “you are crazy” and he would even say, “I was lazy”. (Kay)

Everything kept coming back normal. Nothing was showing up in any of the tests, and it had gotten to where doctors thought I was crazy, my family thought I was crazy, uh.. that I was a hypochondriac, and there was nothing wrong with me and it was all in my head. (Mary)

My husband at the time looked at me like I was crazy and that I was lazy because I didn't want to work. He told me, ... "you know the doctors can't find anything wrong with you, all your tests are coming back normal, maybe it is in your head, ... and you need to see a psychologist." (Sara)

The stigmatization was clearly expressed in the narratives of Kay, Sara, and Mary. Physicians and significant others had tried to assign labels of “crazy” and “lazy” to these women. Such labels, if allowed, can penetrate the soul and cause feelings of embitterment and the questioning of one’s sanity and identity (Blom et al., 2012). This questioning of one’s sanity harkens to Carroll’s (1865) literary character Alice’s thoughts as she struggled to fit through the garden door. Having experienced multiple physical changes, growing too big or too small, Alice delved into deep contemplation concerning her identity:

I wonder if I've been changed in the night. Let me think. Was I the same when I got up this morning? I almost think I can remember feeling a little different. But if I'm not the same, the next question is 'Who in the world am I?' (Carroll, 1865, p.8).

The above helps us to further understand what it means when one feels as though they are going crazy. For these three women, living with FMS has caused tremendous change in their lives--changes so significant that they have wondered, like Alice, who they are in this world?

“Losing”

When we use the phrase “to lose,” the meaning of the phrase may refer to the inability to find something, failing to keep control or hold onto, suffering deprivation, or even failing to win (Merriam-Webster.com, 2013). Women with FMS are confronted with major lifestyle changes that impact their quality of life and that of their families.

Receiving a diagnosis of FMS is often perceived as the death of a lifestyle (Schoofs et al., 2004).

Women with FMS endure exhaustive fatigue, generalized bodily pain, alterations in physical functioning and difficulty with memory; often called “fibro-fog” (National Fibromyalgia Association, [NFA], 2015; Wolfe et al., 1990; Wolf et al., 2010). The clinical manifestations have a detrimental impact on individuals’ ability to rely on their bodies to perform daily activities at the same level as before their diagnosis. Women with FMS experience loss of pleasurable activities, loss in belief in the healthcare system, loss of jobs, and loss of time spent with friends and families (Dow et al., 2012; Lempp et al., 2009; Schoofs et al., 2004).

All three women vividly described the loss they faced in the challenge of living with FMS. Sara, who is young, described how the decline in her physical functioning interfered with her ability to perform routine daily activities and enjoy social events, culminating in the feeling that she was an “older women”:

I’ve had to take a motorized cart just to get groceries, because I was so tired, I didn’t have the energy. I’m not an older woman, but that’s what my body is, my body is an older woman. People try to make future plans with you and you’re like “uhmm...it depends upon how I’m feeling when I wake up that day.” You can’t be dependable to people, it’s very difficult. My kids will want to do something, and I’ll say, “mommy can’t... because she is too tired, or... mommy is hurting too bad.” My youngest had to start making her own peanut butter and jelly sandwiches. It caused a problem between her father and me. He didn’t feel like I was being a responsible parent at the time.

Sara suffered an incapacitating level of mental and physical fatigue that affected her ability to socially interact and caused conflict in her family life. She came to a point where she lamented her inability to even go outside and play with her children. The

routine demands of caring for a family had become overwhelming. Later in Sara's narrative she shared the experience of fighting for disability and the loss of her marriage that followed:

I had been fighting for disability. All in all, I was doing it all alone by myself. My doctors didn't believe me, my family didn't believe me, ...my friends were not there for me. I had no support. I even lost my husband. I went through a divorce.

Difficulty in physical functioning and weakness was a common thread in the participant's narratives and eventually lead to the loss of professional advancement or jobs for all three women. For Kay and Mary, their experience of loss in ability to perform at work and fulfill family responsibilities lead to feeling despondent and a state of depression. This is captured in the following description from Mary:

I had chosen to leave my job and retire, and I was in bed quite often and my flares were getting worse. I had given up. I asked myself, "Will I ever work again? Am I disabled person?" (Mary)

The narratives of Kay, Sara, and Mary help us to understand that the experience of loss was and continues to be prevalent in their lives. Social isolation, unemployment, loss of relationships with spouses, family and friends illustrates that loneliness often infiltrates the lives of individuals with FMS. Through their words, we begin to understand the social implications that ensued for all three women as a result of the debilitating effects of FMS.

"My Best Day"

Receiving support from family members, friends, and HCPs is crucial to individuals with FMS. In chronic illness, the effects of positively perceived social support have been correlated with increased psychological adjustment to illness and increased functional status (Franks et al., 2004). In a qualitative study that explored FMS client's

perceptions of positive and negative physician-client interaction, the characteristics of positive support that were identified by the participants were display of empathy, sympathy, understanding, and compassion. Additionally, receiving acceptance that FMS is a legitimate illness was a primary concern for the respondents (Egeli et al., 2008). Lempp et al. (2009) emphasized clients with FMS rely on a medical diagnosis to validate their symptoms and provide support for their “sick role” to family, friends, and co-workers.

All three women in this study described a pivotal point in their lives in which they received support from a family member, fellow support group members, or a HCP. Gaining acknowledgement that their symptoms were real stood out as personal breakthrough for all three women. Kay described her “best day”:

My best day was when I met my internist. In the first five minutes, I could tell she was a person who would listen to me. As I talked, she would nod her head and say, “you have fibromyalgia real bad.” She listens to you, and she wants you to have the best life you can have.

Sara’s experience was similar to Kay’s experience, in that after an extended search, she found a HCP who conveyed genuine interest in helping her with managing the symptoms of FMS. Sara emphasized how her HCP listened to her words:

He (physician) listens to how you are feeling, he listens to what you are trying to say, even though I’m sure he has heard it time and time again,.. the same symptoms. He tries to come up with a plan with you.

Mary shared in her narrative the multiple times in her life in which the pain from her fibromyalgia had escalated, causing uncontrollable anxiety to the point of “giving up.” It was during these times, her husband’s commitment to joining Mary in her battle with FMS provided her with the strength to face another day. Mary spoke of the significance of her husband’s support and how it made a difference in her life:

My husband is one of those supporters that has undying loyalty, love, and ability to persevere...and a lot of divorce happens because of fibromyalgia. Ours is not one of them...he took the other route.... and instead of saying I can't do this, he decided that he is going to be there...forever... no mater what. My husband jumped in full force...and he became a really significant part of my care.

“Hope: I Can Do This”

Fibromyalgia has been an overwhelming illness for Kay, Sara, and Mary. We have learned of their struggles along the journey with FMS and the multiple times in which this illness has engulfed their lives. Kay, Sara, and Mary’s journey began with the search for a diagnosis and traversed a myriad of human experience. However, the women’s fortitude was a propelling force that assisted them with reaching a place of support and relief from their daily physical and mental anguish.

As the three women shared their experiences of living with and seeking treatment for FMS, an overarching theme of “hope” began to emerge. The hope was manifested in many ways; a hope that their uncertainty would be alleviated, a hope that the world would believe and understand their pain, a hope that they could endure the physical and mental pain of FMS, and a hope that they could survive another day. We heard in their voices that finding support through a HCP, significant other, or support group decreased their state of uncertainty, brought hope, and ultimately empowered each of these women in such a way that they were able to face the reality of living with a relentless, invisible, and incurable illness.

In the previous section, “My Best Day”, Kay and Sara revealed encounters with HCPs who demonstrated concern for their well-being and willingness to actively listen to their health concerns. These specific interactions proved to be monumental in their lives.

Kay's experience of hope illuminated as she spoke of this day:

She (Kay's HCP) said, "I'm going to get you some help." This was such a relief. I said... 'whatever you say, I'll do it.' She could say "you need to go to the edge of the river and kneel down and pray", and I'd do it. She saved my life. I thank God, she saved my life.

Mary used the phrase "I can do this" as she described how her husband's words empowered her and changed her way of thinking about her illness. Mary's husband's words instilled hope. A hope so significant that it allowed Mary to recognize she possessed the inner strength to persevere and not succumb to a path filled with defeat.

He (Mary's husband) would say, "you need to take a different look at this," and that is when I said, 'I can do this.'

Sara's experience of hope was similar to Mary's in that the hope surfaced in a way in which some would refer to as an epiphany. Sara's experience of hope was profound as she reflected on the day that the fibromyalgia support group became an integral part of her life:

The support group is my fibro family. We are really close. They understand...they know how I feel....they are who I go to for direction.

Earlier in Sara's narrative, we learned of her experience of intense isolation. For Sara, the support she received from her "fibro family" provided her with hope. She was not alone.

Discussion

Despite the hope that was experienced by Kay, Sara, and Mary, these women awoke each morning unsure of how fibromyalgia would impact their day. Mary's description highlights the unpredictability experienced with FMS:

Everyday is a new assessment. When I feel like I can get out of bed, I ask myself, 'am I in pain when I open my eyes, can I keep my eyes open?' You know instantly what the day is going to be when you sit up and feel what

your body is like. This goes on throughout the entire day, ... 'what can I do and what can't.. I do?'

Kay, Sara, and Mary's narratives were filled with deep descriptions that revealed the power of client-HCP interactions and how those relationships exacerbated or reduced the uncertainty regarding FMS. Their descriptions revealed that uncertainty persisted, even after receiving a diagnosis and treatment, due to the chronic, ambiguous nature of FMS.

The uncertainty shared among these women is congruent with Mishel's (1990) RUIT. To address the experience of living with persistent uncertainty in chronic illness, Mishel explored the concept of uncertainty in illness (UIT) (Mishel, 1988). The RUIT (1990) emphasized that the individual suffering from a chronic illness is unable to predict future events, and that the uncertainty experienced with chronic illness has unique properties and must be differentiated from the uncertainty experienced with acute illness. Mishel (1990) emphasized that the uncertainty in chronic illness continues after diagnosis and treatment due to the unforeseeable, inconsistent symptoms that may reoccur or exacerbate at any given time.

In Mishel's (1990) RUIT, a HCP's provision of information for clients concerning diagnosis, clinical manifestations, and treatment is an antecedent to uncertainty and also a resource that facilitates the client's ability to cope with the uncertainty experienced with chronic illness. Due to the persistent nature of uncertainty in chronic illness, the outcome of Mishel's (1990) RUIT focuses on the individual's development of probabilistic thinking and achievement of a new worldview. Mishel proposed that when individuals with chronic illness engage in probabilistic thinking, uncertainty becomes a natural way of life (Mishel & Clayton, 2008).

Although this pilot study did not address specific questions concerning adjustment to illness and integration of illness uncertainty, the participants' experiences of living with and seeking treatment for FMS revealed that living with FMS moves beyond the experience of pain. We learned that in addition to the relentless pain, and multiple comorbidities associated with FMS, these women lived in a continual state of uncertainty. We heard in the voices of Kay, Sara, and Mary that FMS and their uncertainty in illness affected multiple dimensions of their lives and exacerbated their levels of anxiety and lead to self-doubt.

However, each of the women also revealed the experience of hope. The hope that the uncertainty in living with FMS would be alleviated or reduced was prevalent. They emphasized that receiving support from family, friends, and HCPs were pivotal points in their lives in which the support provided them with the strength to cope and persevere. Relationships with HCPs stood out as a salient experience among the women that had both positive and negative impact on their level of uncertainty in illness.

The findings from this pilot study will contribute to the literature and deepen understanding of society and the healthcare profession concerning the experiences of women living with and seeking treatment for FMS. Furthermore, an increased level of awareness and understanding of this phenomenon may facilitate a re-awakening in the healthcare profession in reference to the critical need to improve client-HCP communication. Importantly, enhanced insight and understanding of the lived experience of women with FMS may facilitate HCPs with recognizing the importance of assessing the individualized needs of their clients to determine the best approach for managing the complex symptoms of FMS.

Additionally, the findings from this study may assist with development of instruments to measure quality of the client-HCP interaction. Instruments of this nature will (a) provide a source of feedback to HCPs concerning their communication skills and interactions with individuals with FMS; (b) enhance HCP's knowledge concerning client's healthcare priorities and; (c) increase HCP's awareness of the need to strengthen the quality of client-HCP relationships in women with FMS.

CHAPTER III

CLIENT-HEALTHCARE PROVIDER COMMUNICATION IN WOMEN WITH FIBROMYALGIA SYNDROME: RELATIONSHIPS WITH ILLNESS UNCERTAINTY, HELPLESSNESS, AND SUBJECTIVE WELL-BEING

Background and Significance

The purpose of this study was to examine the relationships among client-health care provider (HCP) communication, illness uncertainty, helplessness, and subjective well being (SWB) in women with fibromyalgia syndrome (FMS). FMS is a chronic pain disorder characterized by uncertainty in etiology, symptomatology, diagnosis, treatment, and outcome (Grob, 2011; Madden & Sim, 2006; Reich et al., 2006). The hallmark symptoms of FMS consist of widespread musculoskeletal pain, stiffness, and extreme fatigue. Additionally, individuals with FMS experience an assortment of concomitant conditions covering musculoskeletal, rheumatologic, neurological, gastrointestinal, and psychological domains (Wierwille, 2012; Wolfe et al., 1990; Wolfe et al., 2010).

Nursing theorist Mishel (1990) conceptually defined illness uncertainty as a perceived state of ambiguity that evolves from having a chronic illness with unpredictable symptoms, unknown etiology, and uncertain trajectory. Mishel emphasized that uncertainty is not an emotional response to illness, but rather a cognitive state that can impair the individual's adjustment to illness. The theorist explained that the unrelenting uncertainty experienced with chronic illness impinges upon all aspects of daily life and thus precipitates a sense of chaos. In turn, the turmoil perceived by the ill

individual dismantles their ability to assign meaning to illness and acts as a catalyst generating further uncertainty (Mishel, 1990; 1999). Moreover, Mishel posited that emotional instability results if the uncertainty escalates to a point beyond the individual's coping capacity (Mishel & Clayton, 2008).

Researchers have used Mishel's (1988;1990) uncertainty theories to study illness uncertainty in persons with chronic musculoskeletal pain (Mishel & Clayton, 2008).

There is widespread agreement that illness uncertainty affects coping mechanisms and quality of life (Akkasilpa, Minor, Goldman, Magder, & Petri, 2000; Anema et al., 2009; Asbring & Narvenen, 2004; Johnson et al., 2006; McNulty, Livneh, & Wilson, 2004; Mishel & Clayton, 2008; Mullins et al., 2001; Reich et al., 2006). However, there are few studies that have examined illness uncertainty and its correlates in women with FMS. The extant data indicate that illness uncertainty is a prevalent source of stress for women with FMS that putatively affects their adjustment to illness (Anema et al., 2009; Johnson et al., 2006; Reich et al., 2006).

Multiple studies have shown that women with FMS experience negative encounters with HCPs as they search for a diagnosis and relief of their symptoms. Participants' narratives reveal the poor quality of communication that transpires through negative client-HCP interactions contributes to illness uncertainty and affects SWB in women with FMS (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Madden & Sim, 2006; Sallinen, Kukkurainen, Peltokallio & Mikkelsen, 2011; Schaefer, 2005; Schoofs et al., 2004; Thorne et al., 2004). Deiner (2000) defined SWB as an individual's assessment of their overall quality of life. Optimal SWB is often equated with feelings of happiness, contentment, and satisfaction in life (Deiner, 2000; McDowell, 2010).

Qualitative inquiry has generated evidence of the impact of negative client-HCP communication on the uncertainty experienced in women with FMS. Yet, there is lack of empirical evidence of distinct relationships among client-HCP communication, uncertainty, coping, and SWB within this population. Therefore, the present study was conducted to address this gap in knowledge and specifically evaluate the potential links among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS.

Uncertainty, Client-HCP Communication, and SWB

According to Mishel's (1990) reconceptualized uncertainty in illness theory (RUIT), a HCP's provision of information serves as an intervention to reduce the client's uncertainty and facilitate the appraisal and management of uncertainty. The theorist explained that the client perceives the HCP as a credible authority figure. Thus, the client places trust and confidence in a HCP to provide accurate and essential information concerning the cause, treatment, and outcome of illness. However, Mishel emphasized that the HCP must first be aware of the sources of the client's uncertainty and then provide contextual cues to increase the client's understanding of illness. Examples of contextual cues include what symptoms a client may experience, or what a client may expect to feel, see, or hear during examinations and tests.

Impaired client-HCP communication is a critical healthcare problem for women with FMS (Briones-Vozmediano et al., 2013; Grob, 2011; Haugli, Strand, & Finset, 2004; Lempp et al., 2009; Thorne et al., 2004). Client-HCP communication is defined as the client's perception of the interaction between the client and their HCP. The interaction involves verbal and non-verbal communication. Body gestures and tone of

voice accompany the exchange of words between clients and their HCPs to convey individual thoughts and information (Charlton et al., 2008).

The literature indicates the uncertain nature of FMS contributes to the communication difficulties experienced between women with FMS and their HCPs. Historical researchers report that the clinical entity of FMS has resided in an abyss between traditional medicine and psychiatry for over 500 years due to its unknown etiology and multiple somatic symptoms (Grob, 2011; Inanici & Yunus, 2004).

Although the American College of Rheumatology (ACR) has established diagnostic criteria for FMS, the ACR criteria are based on the client's subjective report of symptoms (Weirwille, 2012; Wolfe et al., 1990; Wolfe et al., 2010). Thus, lack of objective data such as specific laboratory markers and radiologic findings to diagnose FMS have contributed to HCPs' skepticism of FMS (Briones-Vozmediano et al., 2013; Gard & Deodhar, 2012; Hayes et al., 2010; Perrot et al., 2012).

Previous studies have documented HCPs' incredulity in FMS (Grob, 2011; Hayes et al., 2010; Inanici & Yunus, 2004; Peterson, 2007). Hayes et al. conducted a multi-disciplinary needs assessment to discern HCPs' challenges and perspectives regarding the delivery of care for FMS clients. The research participants included 189 general practitioners (GPs), 139 healthcare specialists, and two nurses. The group of healthcare specialists was comprised of rheumatologists, psychologists, neurologists, and anesthesiologists. Hayes and colleagues found that one-fourth of the GPs and one-tenth of the specialists perceived that their FMS patients were malingerers.

The literature indicates there are numerous barriers to healthcare for a person with FMS. However, multiple researchers have found women with FMS persist in their search

to find a HCP that will provide confirmation of their illness and assist with the management of their symptoms (Annemans et al., 2009; Bernard, Prince, & Edsall, 2000; Briones-Vozmediano et al., 2013; Egeli et al., 2008; France et al., 2008; Lempp et al., 2009; Perrot et al., 2012; Schaefer, 2005; Thorne et al., 2004). Studies have found, on the average, FMS clients have experienced symptoms 2.3 years and have consulted with approximately three to six HCPs before a diagnosis is made and treatment is prescribed (Annemans et al., 2009; Perrot et al., 2012).

Perrot and colleagues (2012) surveyed 1622 physicians concerning their experiences and perceptions of diagnosing and treating persons with FMS. The researchers reported that 53% of the physicians perceived challenges in diagnosing and treating FMS clients. In addition to lack of standardized diagnostic criteria as major obstacle to diagnosis, many of the physicians perceived that FMS clients' difficulty in articulating symptoms hindered their ability to make an accurate diagnosis and prescribe effective treatment.

While there is evidence that healthcare is challenged for women with FMS due to diagnostic shortcomings, other researchers propose negative client-HCP communication is the main contributor for the delayed healthcare experienced by women with FMS (Wolfe, 2009). Evidence supporting this inference is found in findings of phenomenological studies of women with FMS. Participants' narratives reveal that seeking healthcare for FMS is often a pilgrimage from one HCP to another HCP (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Thorne et al., 2004). The salient themes that have emerged from the women's narratives consist of HCP's (a) discrediting the

client's experience; (b) unwillingness to explore treatment options; (c) providing impersonal care; and (d) lack of referrals to other healthcare specialists.

Dow and colleagues (2012) conducted a qualitative study of persons with chronic pain. The sample consisted of men and women who had experienced pain from various conditions, such as osteoarthritis, FMS, stroke, lupus and multiple sclerosis. The researchers found that the participants experienced anger and unresolved frustrations from interactions with multiple HCPs who had dismissed their complaints of chronic pain. The participants reported that they perceived the need to place a strong emphasis on the impact of their pain during the healthcare consultation to gain recognition of their pain from HCPs.

Dow et al. (2012) reported that a HCP's lack of acknowledgement of a client's pain creates a cycle of frustration between clients and their HCPs. The participant's prior experiences of dismissal in the healthcare system led to their perceived need to place an overt focus on pain in their subsequent consultations with new HCPs. In turn, the HCP responded negatively to the participant's focus on pain by averting their attention from the communication of pain to another subject. Overall, Dow and colleagues findings suggest the development of a trusting relationship between clients and their HCPs is essential to facilitating positive client-HCP communication in women with FMS.

While qualitative inquiry has produced the preponderance of the evidence of the impact of client-HCP communication on uncertainty in women with FMS, there are a few quantitative studies that have examined the effects of social support on SWB in women with FMS. Franks et al. (2004) examined the effects of quality and quantity of social support on the psychological and physical well-being of women with FMS. The

researchers found quality of social support outweighed the quantity of social support in predicting decreased distress and higher levels of self-efficacy for function and symptom management in a sample of 568 women with FMS. The social network of the participants included family, friends, and HCPs. Franks et al. explained that social support in women with FMS encompasses various components, including emotional, informational and financial support.

Other researchers have investigated the role of a HCP's informational support in women with FMS. Bernard, Prince and Edsall (2000) found from a survey of 270 participants with FMS that 51% of the participants wanted a HCP who would provide informational support. The researchers noted that a HCP's discussion with a client concerning treatment options promotes confidence in clients concerning their ability to self-manage symptoms and attain of a higher quality of life.

Uncertainty, Functional Status, Pain, and SWB

Although there is a paucity of quantitative research on uncertainty in women with FMS, there is an overall consensus that illness uncertainty is a risk factor for maladjustment to illness in women with FMS (Anema et al., 2009; Johnson et al., 2006; Reich et al., 2006). Johnson et al. found that in the presence of pain, high levels of illness uncertainty decreased the participant's ability to cope with the other symptoms associated with FMS. Similarly, Anema and colleagues found high levels of uncertainty were associated with decreased adaptation in a sample of persons with FMS. However, Anema et al. also found that spiritual well-being served as a coping resource for the participants, as it buffered the effect of uncertainty on poor adaptation.

To discern the effect of illness uncertainty on coping in women with FMS, Reich and colleagues (2006) examined the relationships between illness uncertainty and measures of mental health and coping. The researchers found that illness uncertainty and negative coping behaviors were determinants of depression. For the coping variables, high uncertainty was correlated with avoidant and passive coping. In contrast, uncertainty was not a significant correlate of active coping behaviors. These results mirror findings of other studies that have investigated characteristics of coping in persons with FMS (Bernard et al., 2000; Robinson et al., 2012).

As previously discussed, Bernard and colleagues (2000) explored the perceptions of persons with FMS concerning the role of the HCP in educating and managing FMS. In reference to coping strategies used by the participants to manage their symptoms, Bernard et al. found the majority of the participants used positive coping strategies such as exercise, prayer, relaxation techniques, and positive interpersonal interactions with friends, family members, and HCPs. However, the researchers found 12% used alcohol and approximately one-third reported they had used non-prescriptive drugs to cope with FMS. Likewise, Robinson et al. (2012) surveyed 1700 persons with FMS concerning types of medications used to manage their symptoms of FMS. Despite minimal evidence to support the efficacy of opioids for pain management of FMS, the researchers found that opioids such as oxycodone and morphine were among the most commonly used medications in the sample of persons with FMS.

Other studies have specifically focused on the effects of pain and function on emotional outcomes in women with FMS. Multiple studies have found depression is more prevalent in persons with FMS than persons with other chronic pain disorders

(Haugli et al., 2004; Huber, Suman, Biasi, & Carli, 2008; Schleicher et al., 2005; Shuster et al., 2009; Tander et al., 2008). From these studies it appears the emotional upheaval experienced in persons with FMS is related to multiple factors.

Tander et al. (2008) found degree of functional impairment was an influential component in the evaluation of health-related quality of life (HRQoL) for participants with FMS and rheumatoid arthritis (RA). However, Tander and colleagues reported that the participants with FMS scored significantly worse than the participants with RA on the physical role, social functioning, and bodily pain subscales of the Short-Form-36 (SF-36); a measure of HRQoL developed by Ware (1992). Additionally, there was absence of correlation between FMS participant's tender point count and scores on the SF-36 subscales.

In another study, Schleicher and colleagues (2008) explored the relationships between psychological well-being (PWB), pain, and disability in a sample of women with musculoskeletal pain. Findings were consistent with Tander et al. in that women with FMS perceived more emotional distress than women with RA. Schleicher et al. found within the FMS group, PWB was associated with decreased disability and fatigue, but not pain. Self-acceptance, perceived control, purpose in life, and positive interpersonal relationships were aspects of PWB that significantly predicted disability and fatigue in the FMS participants. The evidence from the aforementioned studies suggests that functional status, perceived control and positive social support contribute more to the prediction of SWB than pain. Furthermore, from these studies it appears the appraisal of optimal SWB in women with FMS is possible even in the presence of pain.

Uncertainty, Helplessness, and SWB

DeVellis and Callahan (1993) conceptually defined helplessness as a state in which individuals anticipate that their efforts will be ineffective. DeVellis and Callahan explained that helplessness evolves as a result of negative outcomes experienced with situations in life that are characterized by uncertainty. Previous research indicates perceived helplessness is an important factor in understanding the psychological adaptation to FMS (Nicassio, Schuman, Radojevic, & Weisman, 1999; Palomino, Nicassio, Greenberg, & Medina, 2007; Reich et al., 2006).

As discussed earlier, the research of Reich et al. (2006) found illness uncertainty was a significant correlate of negative coping and depression. A key finding of the research was that the participant's perceived helplessness played a central role in mediating the relationship between illness uncertainty and depression. These findings are congruent with Johnson et al. (2006) research, indicating illness uncertainty is a risk factor for emotional distress in women with FMS. However, the research of Reich et al. provided beginning evidence that helplessness is a specific cognitive attribute that affects the appraisal of uncertainty in women with FMS.

In a separate study, Palomino et al. (2007) examined the relationships among perceived helplessness, impaired function, pain and depression in persons with FMS. Helplessness uniquely contributed to the prediction of depression over and above the contributions of pain and impaired function. Although illness uncertainty was not a variable examined in the research of Palomino et al. the researchers discussed that the uncertain nature of FMS may have been a plausible reason for the participant's perception of helplessness.

Mishel's (1990) RUIT is congruent with the assertion of Palomino et al. (2007) and the previous research of Reich and colleagues (2006). Mishel posited that an individual's perceived sense of mastery over their environment is a cognitive attribute that affects the appraisal of illness uncertainty (Mishel & Clayton, 2008). Additionally, the qualitative literature has shown that women with FMS experience illness uncertainty and struggle with a sense of helplessness over their illness (Dow et al., 2012; Egeli, et al., 2008; Lempp et al., 2009; Madden & Sim, 2006; Sallinen et al., 2011; Schaefer, 2005; Thorne et al., 2004).

In summary, the culminating evidence indicates the cognitive state of uncertainty along with the intrusive symptoms of FMS impacts SWB in women with FMS. Additionally, the uncertain nature of FMS challenges communication between clients and their HCPs. Moreover, the literature suggests that the attainment of positive coping resources may decrease sense of helplessness and the impact of uncertainty on SWB in women with FMS. However, the relationships among client-HCP communication, uncertainty, helplessness and SWB have not been previously examined in women with FMS. Mishel's (1990) RUIT supports the notion that there are distinct relationships between these constructs.

Conceptual Framework

A modification of Mishel's (1990) RUIT was used as the conceptual framework for this study (see Figure 1). Mishel posited that a new worldview is achieved when an individual develops probabilistic thinking and appraises uncertainty as a natural way of life. The theorist explained that probabilistic thinking allows an individual with chronic

illness to abandon the need for absolute predictability. Instead the ill individual views uncertainty as an inherent part of their daily reality (Mishel & Clayton, 2008).

In the model for this study, SWB was the outcome variable. The implicit assumption in Mishel's RUIT is that optimal SWB is achieved when an individual with chronic illness attains a new worldview. In terms of a cognitive trait that affects the appraisal of uncertainty, we were interested in the construct, helplessness, and its role in the appraisal of illness uncertainty in women with FMS. Thus, the role of helplessness as a mediator between illness uncertainty and SWB in women with FMS was examined.

Mishel (1990) inferred that positive client-HCP communication influences the ill individual's formation of a new orientation towards life. In keeping with Mishel's RUIT, client-HCP communication was identified as a resource that facilitates individuals with their adjustment to chronic uncertainty. Specifically, client-HCP communication was posited as a moderator of the relationships between illness uncertainty and helplessness, as well as between helplessness and SWB in women with FMS. Additionally, due to the nature of FMS as a chronic pain disorder that impairs mental and physical function, pain severity, functional status, and illness duration were examined as potential confounding variables of the hypothesized relationships. Functional status was operationally defined in the current study as an individual's overall perception of performance in multiple domains of daily life.

Purpose

The purpose of this study was to examine the relationships among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS. The specific aims of this study were to (1) measure the quality of client-HCP communication,

level of illness uncertainty, helplessness, functional status, pain severity, illness duration, and SWB in women with FMS; (2) evaluate the contribution of helplessness in the relationship between illness uncertainty and SWB in women with FMS; and (3) determine the effect of client-HCP communication on the relationship between illness uncertainty and helplessness, and between helplessness and SWB in women with FMS.

The following hypotheses were tested in the current study:

- H₁ Illness uncertainty is negatively associated with SWB in women with FMS.
- H₂ Illness uncertainty is positively associated with helplessness in women with FMS.
- H₃ Helplessness is negatively associated with SWB in women with FMS.
- H₄ Helplessness mediates the relationship between illness uncertainty and SWB in women with FMS.
- H₅ Client-HCP communication moderates the relationships between illness uncertainty and helplessness, as well as the relationships between helplessness and SWB in women with FMS.

Figure 1. A Modification of Mishel's Reconceptualized Uncertainty in Illness Theory

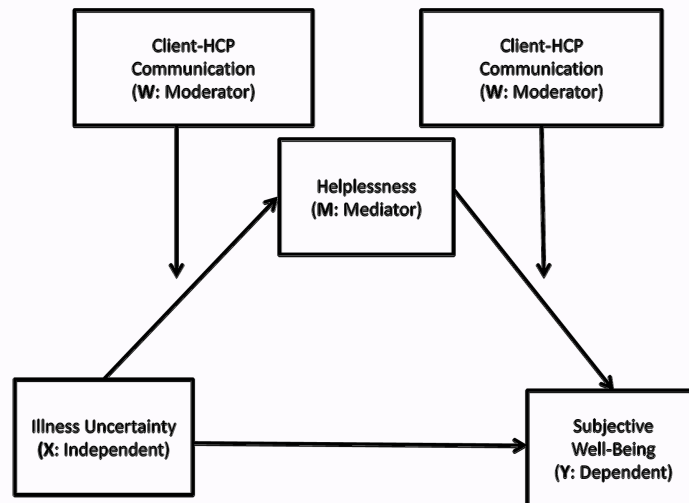


Figure 1. Modification of Mishel's (1990) Reconceptualized Theory of Uncertainty

Methods

Research Design and Sample

A cross-sectional research design was used for this study. Prior to recruitment and data collection, study procedures were reviewed and approved by the institutional review board of the researchers' universities. Participants were recruited from a community located in the southern region of the United States and nationally from online fibromyalgia support groups. Local newspaper announcements and information flyers posted in offices of private HCP practices, campuses of local universities and other public locations were used to advertise for the study in the southern community. National

recruitment strategies consisted of contacting online fibromyalgia support group leaders via telephone or email and asking support group leaders to post the study advertisement information on fibromyalgia support groups' web pages. To enroll in this study, participants had to (a) be of female gender; (b) self-identify as having a confirmed diagnosis of FMS; (c) be at least 18 years of age; and (d) speak and read English.

A total of 161 potential participants contacted the researchers by phone or email and indicated interest in participating in the study. During this initial contact, the study purpose, research process, estimated time for completion of the confidential health surveys, and preamble consent procedures were explained along with an initial screening for inclusion criteria. Of the 161 potential participants, 158 respondents volunteered to participate in the study and indicated that they met the study's inclusion criteria. The enrolled participants were asked if they preferred to receive the confidential health surveys electronically via their email address or via the US postal mail. Of the 158 enrolled participants, 141 participants returned surveys for this study (89% participation rate). The majority of the surveys, 122 out of 141, were completed and returned electronically via Research Electronic Data Capture (REDCap). REDCap is a secure, web-based application designed to support data capture for research studies (Harris et al., 2009). The remainder of the surveys were completed via pencil and paper and returned to the researchers through the US postal mail in the postage paid, self-addressed return envelope that was provided for the participants. Of the 141 returned surveys, three were excluded from the analysis due to missing age and gender data on the demographic questionnaire. Thus, a total of 138 women with FMS composed the sample for this study. This sample size yielded sufficient power (greater than 80%) to test the hypotheses.

Measures

The study involved completing the following six health surveys: (a) demographic questionnaire, (b) Patient Health Care Provider Communication Scale (PHPCS) (Salt et al., 2012), (c) Mishel Uncertainty in Illness Scale- Community Form (MUIS-C) (Mishel, 1981), (d) The Helplessness Subscale of the Rheumatology Attitudes Index (RAI) (DeVellis & Callahan, 1993), (e) Fibromyalgia Impact Questionnaire Revised (FIQR) (Bennett et al., 2009), and, (f) The General Well-Being Schedule (GWBS) (Dupuy, 1977). Permission was granted to use all copyrighted questionnaires.

Demographic questionnaire. This form was used to obtain socio-demographic data and included questions regarding participants' age, gender, ethnic background, educational level, employment, disability compensation, duration of FMS symptoms, year of diagnosis and type of HCP used for management of FMS.

The quality of client-HCP communication. To our knowledge, there are no known instruments that have been specifically designed to measure the quality of client-healthcare provider (HCP) communication in women with FMS. However, there are a few existing self-report scales that measure the quality of patient-HCP communication in persons with rheumatoid arthritis (RA) (Salt et al., 2012). While the pathophysiology is different for RA and FMS, the literature reveals that both medical populations experience musculoskeletal pain and fatigue and perceive that client-HCP communication as a critical component of quality healthcare (Briones-Vozmediano et al., 2013; Haugli et al., 2004; Salt et al., 2012; Thorne et al., 2004). Because the authors could not identify a measure of client-HCP communication in women with FMS, the Patient Health Care

Provider Communication Scale (PHCPCS) (Salt et al. 2012) was used to measure the quality of client-HCP communication in women with FMS.

The PHCPCS is a 21 item self-report questionnaire originally developed to measure the quality of patient-HCP communication in individuals with RA. The 21 items for the scale were developed from patients' perspectives of quality patient-HCP communication through focus groups and individual interviews. The PHCPCS measures two dimensions of patient-HCP communication: quality communication and negative patient-HCP communication. Each item is measured on a 4-point Likert type scale (1= *not at all*; 2= *somewhat like*; 3= *much like*; 4= *very much like*). The total scale score is obtained by adding the participant's responses on the 4-point Likert scale. The possible score on the PHCPCS has a range of 21 (participant perceives a low quality of client-HCP communication) to 84 (participant perceives a high quality of client-HCP communication). To obtain additional information from the participants concerning specific aspects of client-HCP communication that they perceived as important, the open ended question 'when I visit my healthcare provider for my fibromyalgia, I wish he/she would' was added to the health surveys after the last item on the PHCPCS.

Salt et al. (2012) reported that content validity for the PHCPCS was assessed by the obtainment of feedback from rheumatologists, a behavioral scientist and a nurse researcher on the appropriateness of the scale items to patient-HCP communication in RA patients. The PHCPCS was written on a sixth grade reading level. Additionally, the scale developers reported face validity for the PHCPCS was established based on patient's opinions concerning readability and comprehension (Salt et al., 2012). Results of correlational analysis between the Perceived Involvement in Care Scale (PICS) (Lerman,

Brody & Caputo, 1990) and the PHCPCS total scores and subscale scores provide modest evidence to support construct validity for the 21 item PHCPCS. The PHCPCS has demonstrated strong internal consistency reliability. In a study of 150 RA patients, the total PHCPCS had a Cronbach's alpha of 0.89. Alphas for the subscales, Quality Communication and Negative Patient-HCP Communication, were reported as 0.94 and 0.73 respectively (Salt et al., 2102). In the current study, the total PHCPCS exhibited a strong reliability coefficient (Cronbach's alpha 0.97). The Cronbach's alpha for the 17 items composing the Quality Communication subscale was 0.98; Cronbach's alpha for the Negative Client-HCP communication subscale was 0.78.

Illness uncertainty. The MUIS-C (Mishel, 1981) was used to measure the participant's perceived level of illness uncertainty. The MUIS-C is a self-report, 23 item scale that was designed to measure four components of illness uncertainty: ambiguity, complexity, inconsistency, and unpredictability. Respondents rate agreement or disagreement with each item based on a 5-point Likert type scale with 1=*strongly disagree* to 5=*strongly agree*. Responses to all items are totaled to obtain a single composite score ranging from 23 to 115, with higher scores reflecting a greater level of uncertainty. The MUIS-C has been widely used in various health related populations. Previous studies of women with FMS have documented the MUIS-C as a valid and reliable measure. Cronbach's alphas have ranged from 0.74 to 0.92 in previous studies (Anema et al., 2009; Johnson et al., 2006; Reich et al., 2006). In the current study, the MUIS-C exhibited strong internal consistency reliability with a Cronbach's alpha of 0.90.

Helplessness. The 15-item Rheumatology Attitudes Index (RAI) developed by DeVellis and Callahan (1993) contains a five-item Helplessness subscale. The instrument

was designed to assess a client's perception of helplessness about coping with rheumatic illness. Each item on the RAI Helplessness subscale is measured using a 5-point Likert scale with 1=*strongly disagree* to 5=*strongly agree*. Higher scores indicate greater levels of helplessness. Item number 4 is reverse coded and the sum of all items yields a total score. The RAI has been used in various chronic illness populations such as osteoarthritis, multiple sclerosis, systemic lupus erythematosus, scleroderma and fibromyalgia. Evidence of construct validity was documented with a correlation coefficient of 0.79 between the full RAI and the RAI Helplessness subscale. In addition, the RAI Helplessness subscale has demonstrated good internal consistency reliability in previous studies with Cronbach's alpha ranging from 0.67 to 0.70 (Brady, 2003). The RAI Helplessness Subscale performed well in the current study with a Cronbach's alpha of 0.77.

Functional status. The FIQR (Bennett et al., 2009) contains 21 questions that measure the same domains as in the original fibromyalgia impact questionnaire (FIQ): physical function, overall impact of the FMS, and symptoms of FMS. However, additional questions were added to the FIQR to account for associated symptoms of FMS such as tenderness, balance problems, difficulty with memory, and environmental sensitivity. Overall, the literature indicates the FIQR serves as an equivalent online health survey to the original pen and paper version of the FIQ (Boomershine, 2011).

The directions of the FIQR are self-explanatory and participant completion time for the FIQR is reported as 1.3 plus or minus 0.02 minutes. The score range of the FIQR is 0-100 and is calculated from the three domain scores with higher scores indicating increased severity of FMS. An 11-point numeric rating scale of 0-10 with 10 representing

more severe impact of FMS on function is assigned to all questions of the FIQR (Bennet et al., 2009). The first item in domain three, the symptom domain, addresses pain level. This specific item in domain three was used to measure the participant's pain intensity in the current study.

The FIQR has reliable psychometric properties. Results of correlational analysis between the items of the FIQR, FIQ, and SF-36 survey, a measure of quality of life (Ware & Sherbourne, 1992) provide evidence to support FIQR validity. Previous studies have documented a Cronbach's alpha of 0.95 and item total correlations ranging from 0.56-0.93 (Bennett et al., 2009). In the current study, the FIQR exhibited strong internal consistency reliability with a Cronbach's alpha of 0.92.

Subjective well-being. The GWBS developed by Dupuy (1977) as a measure of subjective feelings of PWB and distress is a self-report questionnaire comprised of 18 items that assess positive and negative feelings of the inner personal state. The first 14 items of the GWBS use a response scale ranging from 1-6 that represent intensity or frequency of the respondent's feelings. The last four items contain a rating scale from 0-10 with 0= *not concerned at all*, and 10=*very concerned*. The polarity of the items 1, 3, 6, 7, 9, 11, 13, 15 and 16 is reversed for scoring purposes to allow for a lower score to represent severe distress, and a higher score to represent positive well-being. The six dimensions identified by Dupuy (1977) are anxiety, depression, positive well-being, self-control, vitality, and general health. Subscale scores and a total score can be calculated. A total score is calculated by subtracting 14 from the total running score of 0-124 to yield a final score of 0-110. The three categories that represent levels of PWB or distress derived

from cutting points are: 0-60 = *severe distress*, 61-72 = *moderate distress*, and 73-110 = *positive well-being*.

The GWBS has demonstrated strong internal consistency reliability. McDowell (2009) reported that previous studies have documented Cronbach's alpha ranging from 0.90 to 0.95 and alphas above 0.70 for the subscales. Results of large factor analysis studies support the original dimensions of the scale. However, recent literature suggests the GWBS is unidimensional due to the high internal consistency exhibited by the GWBS (McDowell, 2009). In the current study the total GWBS exhibited strong internal consistency reliability, with a Cronbach's alpha of 0.92.

Data analyses

Data were analyzed with IBM Statistical Package for Social Science (SPSS) software version 20.0. First, the data were summarized and explored. Overall, the missing values were random. It was determined that each variable had less than 3% missing data. The samples' item mean values were imputed for scales that had less than 25% missing data. The scores for the MUIS-C, RAI Helplessness subscale, FIQR, pain severity, and GWBS were normally distributed. The distribution of scores for the PHCPCS were flat and negatively skewed indicating the majority of the participants perceived a high quality of client-HCP communication.

The first aim of this study was accomplished with the use of descriptive statistics. Descriptive statistics were conducted for the entire sample with means, medians, standard deviations, and ranges for all continuous variables and frequencies and percentages for all categorical variables. Pearson Product Moment Correlations were used to examine the bivariate correlations of the continuous study variables. The second and third research

aims were addressed by conducting a series of multiple regression analyses to examine the relationships among the study variables and explore the models. Preliminary analyses were conducted prior to the multiple regression procedures to ensure there were no violations of the assumptions of normality, linearity and homoscedasticity. The alpha level for the statistical tests was set at 0.05.

Testing of model 1, mediation. Prior to conducting the analyses, the variables in the model were centered. We centered the variables to decrease multicollinearity and thus, facilitate the interpretation of the regression coefficients. The centering involved subtracting the sample mean of the variable from the variable. This process created a centered variable in deviation score form with a mean of zero for each variable (Lindley & Walker, 1993).

Three separate multiple regression equations were conducted to evaluate whether helplessness was a mediator between illness uncertainty and SWB (See Figure 2 for assumed structure for mediation). Separate coefficients for each regression equation were estimated and tested as described by Baron and Kenny (1986). In the first equation, the outcome variable, SWB was regressed on illness uncertainty (Path c), and on each of the covariates, functional status, pain severity, and illness duration. In the second regression equation, helplessness was regressed on illness uncertainty (Path a), and on each of the covariates. In step three, with the third regression equation, SWB was regressed simultaneously on illness uncertainty, helplessness, and the covariates. To confirm the significant indirect effect of illness uncertainty on SWB through helplessness (Path c'), a Sobel test (1982) was computed using an online interactive calculation tool provided by Preacher (2015).

Figure 2. Model 1. Assumed Structure for Mediation

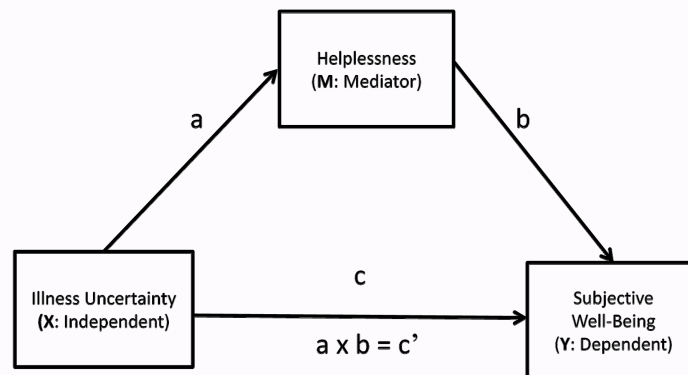


Figure 2. Model 1. Assumed structure for mediation.

Testing of model 2, moderated mediation. A multiple regression procedure using an SPSS macro, MODMED, provided by Preacher, Rucker, and Hayes (2007) tested for moderated mediation (See Figure 3 for assumed structure of moderated mediation). Specifically, the regression procedure tested whether client-HCP communication and illness uncertainty and their interaction as independent variables predicted helplessness, and whether client-HCP communication and helplessness and their interaction predicted SWB. Functional status, pain severity and illness duration were added as covariates. The data generated from the multiple regression procedure were analyzed to determine if there were significant moderator-interaction effects in the model. We based the need for further analysis of moderated mediation on the evidence of significant regression coefficients for either of the interaction terms. (Preacher et al., 2007).

Figure 3. Model 2. Assumed Structure for Moderated Mediation Model

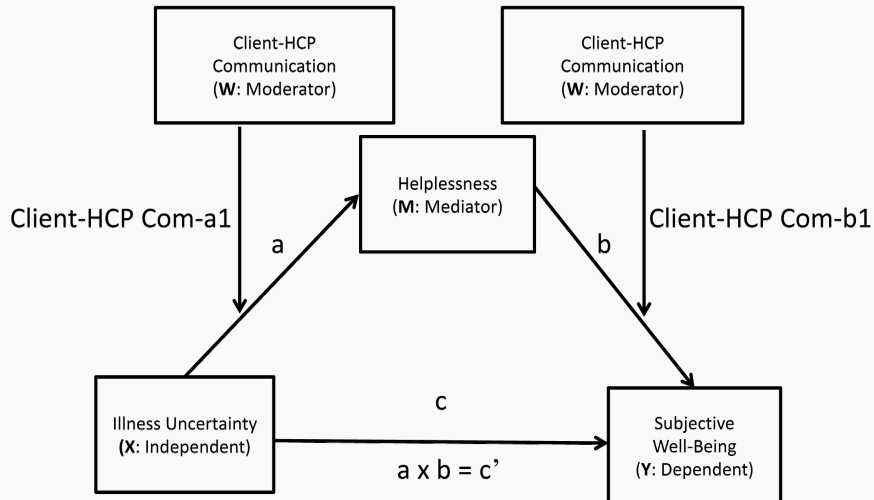


Figure 3. Model 2. Assumed structure of the moderated mediation model

Analysis procedure of narrative data. The participant's written responses to the open-ended question concerning client-HCP communication were read and reviewed several times by the primary investigator. Each participant's response was assigned a code. The coded data were examined for commonalities and the presence of themes. To ensure trustworthiness of the data, a second reviewer reviewed the narrative text independently and met with the primary investigator to discuss the identified themes.

Results

Sample Characteristics

The mean age of the women in this study was 53.2 years (standard deviation (*SD*) = 12.4) with a range between 20 to 82 years of age. Caucasians accounted for 91% of the participants ($n = 138$). The majority of participants had completed a 4-year college degree

or higher. Fifty-nine percent of the participants were unemployed. Yet, only 18% reported receiving disability-related compensation.

On average, the participants had experienced symptoms of FMS for 17.4 years, with a range from 6 months to 60 years. While 88% of the participants experienced FMS symptoms greater than 5 years, only 55% reported receiving a diagnosis of FMS within the past 10 years. The data suggest for some of the participants there was a gap between onset of symptoms and the receiving of a diagnosis.

The majority of the participants received care for their FMS from a physician. A small percentage, 4%, received care from a chiropractor and 17% reported that they received care from other healthcare specialists and complimentary therapy providers. The types of HCPs specified by the participants varied and included nurse practitioners, pain management specialists, psychiatrists, rehabilitation specialists, acupuncturists, massage therapists, naturopaths, and one endocrinologist (See Table 1 for summary of the socio-demographic characteristics).

Analyses of Study Variables

Univariate analyses. The mean score on the MUIS-C in the present study was high ($M = 70.0$, $SD = 14.77$) indicating the majority of the participants perceived a high level of illness uncertainty. Likewise, on the average, the participants experienced high levels of helplessness ($M = 17.45$, $SD = 4.26$). In addition, the majority of the women in this sample experienced high levels of pain and a high degree of impairment to their daily function. The mean pain severity score and mean total FIQR score were ($M = 6.58$, $SD = 1.84$) and ($M = 60.58$, $SD = 16.2$) respectively. In reference to the outcome variable,

SWB, the mean score for the total GWBS was 48.72 ($SD = 18.54$) indicating the majority of the women perceived severe distress.

Bivariate analyses. The bivariate relationships between the predictive variables in the model were explored using Pearson product-moment correlation coefficients. High scores on illness uncertainty correlated with low scores on SWB ($r = -.43, p < 0.0001$). There was a positive correlation between illness uncertainty and helplessness ($r = .59, p < 0.0001$) and high scores of helplessness correlated with low scores on SWB ($r = -.63, p < 0.0001$). In addition, there was a positive correlation between client-HCP communication and SWB ($r = .24, p = 0.003$).

Using guidelines provided by Cohen (1988), it was determined that the strength of the correlation between SWB and client-HCP communication was small ($r = .24, p = 0.003$). The largest inter-correlations were between helplessness and functional status ($r = .71, p < 0.0001$), pain severity and functional status ($r = .68, p < 0.0001$), helplessness and SWB ($r = -.63, p < 0.0001$), and functional status and SWB ($r = -.61, p < 0.0001$) (See Table 2 for the bivariate correlation matrix of predictor variables).

Multivariate analyses. Model 1 mediation results. The testing of Path c in the first regression equation revealed a statistically significant relationship between the predictor variable, illness uncertainty and the outcome variable SWB ($B = -.26, p = 0.018$) when controlling for functional status, pain severity and illness duration. The unstandardized estimate of regressing the mediator helplessness, on illness uncertainty was significant (path a) ($B = .10, p < 0.0001$) when controlling for each of the covariates. In the last regression equation, when controlling for illness uncertainty, and each of the covariates, helplessness predicted SWB (Path b) ($B = -1.439, p = 0.010$). In addition, the

previously significant relationship between illness uncertainty and SWB (Path c') became non-significant when helplessness was entered into the regression equation ($B = -.12, p = 0.332$). The forgoing analyses of the parameter estimates suggested helplessness mediated the relationship between illness uncertainty and SWB. Moreover, the Sobel test (1982) yielded a significant effect of illness uncertainty on SWB through helplessness ($Z = -2.334, p = 0.02$) and thus confirmed the mediating role of helplessness between illness uncertainty and SWB. Another notable finding was that results of the semi-partial correlations revealed that functional status also made a unique contribution to the prediction of SWB. However, the contribution of functional status to the prediction of SWB was less than the contribution of helplessness to SWB. The overall model explained 46% of the variance in SWB (See Table 3 for the summary of the regression results).

Model 2 moderation results. Results of the multiple regression procedure using the SPSS macro, MODMED indicated the interaction effect of client-HCP communication and illness uncertainty on helplessness was non-significant when controlling for illness uncertainty, client-HCP communication, functional status, pain severity, and illness duration ($B = .0001, t = .0567, p = 0.955$). Likewise, the interaction effect of client-HCP communication and helplessness on SWB was non-significant when controlling for illness uncertainty, helplessness, client-HCP communication, functional status, pain severity and illness duration ($B = .0165, t = .5128, p = .6095$). Lack of evidence of client-HCP communication as a moderator of the relationships between illness uncertainty and helplessness; and between helplessness and SWB precluded the need for further statistical analyses of moderated mediation (Preacher et al., 2007). (See Table 4 for the results of the multiple regression procedure).

Results of narrative data analysis. The participants' responses to the open-ended question, '*when I visit my healthcare provider for my fibromyalgia, I wish he/she would*', revealed that the majority of the participants had experienced negative encounters with a HCP. This finding was inconsistent with the samples' high mean score on the PHCPCS. The directions on the survey instructed the participants to answer the questions in relation to their current HCP that provided care for their FMS. However, we found that many of the participant's descriptions reflected encounters with multiple HCPs. Two overarching themes emerged from the participants' written responses: "Listen and Believe", and "Provide Me with More Knowledge".

"Listen and Believe". Many of the women described their desire for a HCP that would actively listen to their voices. Another notable finding was that the women's narratives reflected that they wished for a HCP that would not only listen, but and believe in their symptoms and appraisal of their illness. In the following narrative, this particular participant reflected a sense of relief when finding a HCP that validated her illness.

"My current doctor is awesome! She listens, provides information, and is open to methods of treatment/management outside of her expertise. In the past this has not been true with other doctors. What I wish they would have done is... listen, believe me about my pain, not make me feel like it was all in my head, and look for the cause of my condition."

Other participants wrote about experiences with HCPs that had either blamed all of their health problems on FMS or had attributed their FMS symptoms to a psychiatric disorder. The following excerpts reveal HCPs' lack of listening and dismissal of the participants' symptoms led to feelings of frustration and mistrust in the healthcare system:

I wish my HCP would stop referring to my "anxiety" and "depression" so much, as I felt as if he thought that was the major reason for my diagnosis of fibromyalgia. I had to continuously tell him that I did not become depressed until these past couple months, because I feel debilitated by pain.

I wish for HCPs to be honest, I gave up on most Western medicine. Nothing was helping, and Western doctors either tried to medicate me or give me injections. They often had no time to listen, and were often blaming everything on fibro. I actually had a gallbladder issue-they blamed fibro.

I wish my HCP would listen and acknowledge Fibro is real! My primary care provider (PCP) stated it's the "woman's day magazine disease of the month" when I first told him I had been diagnosed by a Rheumatologist.

“Provide Me with More Knowledge”. A majority of the participants’ written responses reflected their wish for more knowledge from their HCP. Additionally, we found that the participants wrote about their need for specific information from HCPs. For example, many of the women expressed that they wished that their HCP would be more knowledgeable of therapies outside of the pharmaceutical approach to FMS. The narratives below capture the theme “Provide Me with More Knowledge”. In these passages, the participants reflected upon how lack of HCPs’ knowledge of alternative therapies or lack of discussion of potential therapies precipitated their need to search on their own to find symptom relief:

I wish my HCP would truly make herself more knowledgeable. FMS is not black or white or cut and dry answers, as in other medical conditions. Alternatives should be in the forefront and honesty about being/not being able to help. A plan of treatment would be wonderful. I feel totally "on my own" to figure out a lot of issues.

I wish my HCP would be the one to initiate the treatment options. Most often, it is me who is there asking about a treatment that I have heard about because of the research that I do on my own. She is normally willing to try it, but does not seem to be that knowledgeable about it.

Another prevalent finding concerned the women's wishes for a HCP that would provide them with knowledge to facilitate their coping with FMS. The following narrative suggests that the acquisition of knowledge may serve as a source of encouragement and empowerment for women with FMS:

I wish my HCP would talk to me about what if any new information is available and help me learn how to deal with my illness, to give me hope. Not just treat the pain or issue with medication... but give me more insight on how I can feel better or have a better quality of life.

Discussion

This study examined the relationships among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS. Specifically, two predictive models were evaluated. The mediating effect of helplessness on the relationship between illness uncertainty and SWB was examined in the first model. In the second model, the moderating effects of client-HCP communication on the relationships between illness uncertainty and helplessness and between helplessness and SWB were also evaluated. Pain severity, functional status, and illness duration were also evaluated as confounding variables in both models. Additionally, narrative data concerning client-HCP communication were analyzed.

Helplessness as a Mediator

The data from this study supported the posited mediating effect of helplessness on the relationship between illness uncertainty and SWB. Although illness uncertainty was a significant predictor of SWB initially, illness uncertainty did not uniquely contribute to the prediction of SWB when helplessness was included in the regression equation. We found helplessness demonstrated the strongest unique contribution to SWB over and

above the contributions of illness uncertainty, functional status, pain severity, and illness duration.

The current study's findings contribute to the literature by strengthening the existing evidence concerning the effect of helplessness on the appraisal of illness uncertainty in women with FMS. The data suggest that while illness uncertainty is associated with emotional distress in women with FMS, it is the individual's perceived sense of helplessness that strongly influences the impact of illness uncertainty on SWB. To our knowledge, Reich and colleagues' (2006) study comprises the only other research on the relationships among illness uncertainty, helplessness, and emotional outcomes in women with FMS. Our findings are consistent with the findings of Reich et al. and provide further evidence concerning the key role that helplessness plays in the appraisal of illness uncertainty and attainment of SWB in women with FMS.

With respect to the impact of functional status on the relationships among illness uncertainty, helplessness and SWB, the current study's results showed that the participant's perceptions of the impact of FMS on their daily function made a significant contribution to the predictions of perceived helplessness and poor SWB. Examples of daily functions that were rated by the participants on the FIQR included sleeping, walking, sitting, styling of hair, preparing meals, routine household chores, climbing of steps, and grocery shopping. Indeed, functional status showed a statistically significant relationship with illness uncertainty, helplessness, pain severity, and SWB.

However, we found that the strongest correlations were between functional status and helplessness, and between functional status and pain severity. Moreover, functional status retained its significant relationship with helplessness when controlling for

uncertainty, pain severity, and illness duration. Likewise, in the final regression of the mediation analyses, functional status retained its significance with SWB when controlling for all of the other variables. Overall, the mediation model explained 46% of the variance in SWB.

The unique contribution of functional status to the prediction of the sample of women's SWB was not surprising considering the existing evidence in the literature of the uncertain, omnipresent nature of FMS. Multiple studies have found women living with FMS experience quandaries concerning the unknown impact of FMS on mental and physical functioning. Participants' narratives from previous studies reveal that the unpredictable symptoms experienced with FMS, often referred to as "fibro-days" or "flares", imposed significant disruption to their activities of daily living. Diffuse pain, disturbed sleep, and exhaustive fatigue were among the multitude of symptoms that waxed and waned in the daily lives of the participants (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Madden & Sim, 2006; Sallinen et al., 2011; Schaefer, 2005).

Additionally, our findings were congruent with those reported by the earlier research of Nicassio et al. (1999) and Palomino et al. (2007) concerning the conjoint contributions of pain, functional impairment, and helplessness on SWB in persons with FMS. Nicassio and colleagues found pain and disability contributed independently to the prediction of depression and thus evaluated helplessness as a partial mediator of the effects of pain and disability on depression. Similarly, Palomino and colleagues found perceived loss in function was a significant predictor of depression. However, more closely aligned with our findings, Palomino et al. determined that helplessness fully

mediated the relationship between pain and depression, as helplessness demonstrated the most unique contribution to depression.

Client-HCP Communication as a Moderator

Contrary to our hypothesis, client-HCP communication did not moderate the relationships between illness uncertainty and helplessness, nor the relationships between helplessness and SWB in the sample of women with FMS. Because our study is the first study that has examined the aforementioned moderating role of client-HCP, there is no data to compare our results. Additionally, there is no previous empirical data to compare the participant's perceptions of the quality of client-HCP communication as measured by the PHCPCS.

However, we were surprised to find that the samples' high mean score on the PHCPCS was inconsistent with the narrative data collected in the current study. The samples' high mean score on the PHCPCS indicated the sample of women with FMS perceived a high quality of client-HCP communication, whereas the majority of the narrative responses to the open-ended client-HCP communication question reflected participant's experiences with negative client-HCP communication.

Yet, the themes that were gleaned from the narrative data in the current study, "Listen and Believe" and "Provide Me with More Knowledge" were found to be parallel with previous findings reported by qualitative researchers. A common theme throughout the qualitative literature concerns FMS clients' struggles for legitimacy and support from HCPs (Thorne et al., 2004). Multiple studies have found women with FMS rely on HCPs to facilitate their ability to understand their illness and manage the complex symptoms of FMS. From these studies, the imminent need of the women with FMS was to find a HCP

that would listen and validate their symptoms and provide them with knowledge to reduce their uncertainty experienced with FMS (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Madden & Sim, 2006; Schaefer, 2005; Thorne et al., 2004).

Analysis of the narrative data revealed that many of the participant's written responses reflected a culmination of experiences with HCPs. This finding helps explain discrepancies between the narrative data and the PHCPCS scores. Previous studies have found women with FMS seek healthcare from multiple HCPs and various healthcare specialties to validate their symptoms, provide a diagnosis, and prescribe effective treatment (Annemans et al., 2009; Briones-Vozmediano et al., 2013; Dow et al., 2012; Hayes et al., 2010; Lempp et al., 2009; Madden & Sim, 2006; Perrot et al., 2012; Schaefer et al., 2005; Thorne et al., 2004).

Thus, based on this evidence, it was possible that the overall perception of high quality client-HCP communication as measured by the PHCPCS was a reflection of communication with a HCP in which the participants had spent many years searching after encountering negative interactions with previous HCPs. Furthermore, the participants' reporting of their experiences with negative client-HCP communication led to our assumptions that the participants wanted their past experiences to be heard and to be understood.

Although the moderating effect of client-HCP communication was not substantiated in the current study, the samples' high mean score on the PHCPCS was an encouraging finding. This specific finding suggests that HCPs have become more aware of the communication priorities of women with FMS that have been previously highlighted in the qualitative literature such as, display of kindness, concern, attention,

honesty, and a non-hurried manner (Egeli et al., 2008; Lempp et al., Thorne et al., 2004). Moreover, the majority of the participant's perceptions of a high quality of client-HCP communication as measured by the PHCPCS suggest that HCPs engaged in positive communication with the women during their healthcare consultations. However, the inconsistencies between the narrative data and the samples' high mean score on the PHCPCS suggest the phenomenon of client-HCP communication was not completely captured by the PHCPCS in the sample of women with FMS. The narrative data showed that the women in the current study wished for a HCP that would listen and believe in their symptoms and provide them with more knowledge.

Our analysis of the individual items on the PHCPCS revealed there are no items on the PHCPCS that contain the words, listen or believe. Additionally, we found that there is only one item on the PHCPCS that addresses the participant's perception of their ability to make a decision about their healthcare based on the quality of a HCP's communication. This content was reflected in item 21 of the PHCPCS, '*Am able to make health-related decisions because of the information provided by my healthcare provider*'. Interestingly, item 21 was among the lower scoring items on the PHCPCS. Based on this evidence, it could be argued that the lack of items on the PHCPCS dedicated to quality components of HCP communication such as a HCP's listening and believing, as well as a HCP's communication that empowers decision making may have accounted for the current study's lack of support for client-HCP communication as a moderator between illness uncertainty and helplessness; and between helplessness and SWB.

Limitations

Several limitations of the current study need to be acknowledged. Because the data was based on self-report, the relationships among the constructs may have been inflated. Given the intrusive nature of FMS and its history as a contested illness by the healthcare profession, it is possible that the majority of women participating in the study were those that suffered the highest impact from FMS and had encountered difficulties with client-HCP communication. The cross-sectional, correlational design of the research also posed a limitation, as causal inferences concerning the direction of relationships among the study variables could not be determined. Conceivably, a primary mood disorder may have contributed to the participant's perceptions of helplessness or may have preceded the participant's perceptions of uncertainty.

Another limitation was that the majority of the sample consisted of Caucasian women with a college degree. However, other ethnic and racial groups with various education levels were represented in the study. Although generalizability of the current study's results cannot be guaranteed, the homogeneity between the participants of this study and the FMS population in reference to demographic characteristics and the high impact of FMS on SWB provides a level of validity for the current research.

Additionally, the measurement of illness uncertainty and its potential correlates at only one point in time was a limitation of the current research. Mishel's (1990) theory asserts that the appraisal of uncertainty in chronic illness is a dynamic process that gradually shifts from danger to uncertainty over time. Therefore, we recognized that the participant's perceptions of client-HCP communication, uncertainty, helplessness,

functional status, and SWB in the current study did not reflect temporal changes perceived by the participants in these constructs.

We included illness duration as a covariate in the predictive models to examine whether illness duration would contribute to the prediction of SWB in the sample of women with FMS. However, illness duration failed to show a correlation with illness uncertainty, functional status, client-HCP communication, and SWB. Although illness duration showed a correlation with helplessness and pain severity, the strength of the relationships were small. Furthermore, illness duration failed to contribute to the overall model in predicting SWB. Lastly, the use of the PHCPCS to measure client-HCP communication was another limitation of the current study. Because this is the first study to use the PHCPCS to measure client-HCP communication in women with FMS, caution should be used when interpreting the results concerning the moderating role of client-HCP communication.

Conclusion and Recommendations

In summary, the current study demonstrated that FMS has a deleterious effect on SWB in women with FMS. Our findings indicate emotional distress experienced in women with FMS is associated with uncertainty, helplessness, loss of function, and pain. Importantly, the findings of this study strengthen the existing evidence in the literature concerning the mediating role of helplessness between illness uncertainty and SWB in women with FMS. Although helplessness is not an exclusive linkage to poor SWB in women with FMS, helplessness is a specific illness cognition that helps explain the relationship between the uncertainty and the mental anguish experienced in women with FMS.

Mishel (1988; 1990) posited that emotional instability results if uncertainty escalates beyond an individual's coping capacity. Furthermore, Mishel discussed that the appraisal of uncertainty and adjustment to illness is affected by the individual's sense of mastery over their environment. The theorist's concept of environmental mastery is similar to the concept of helplessness as described by the early work of Peterson (1982) and DeVellis and Callahan (1993). Peterson (1982) contended that a sense of helplessness over a situation evolves when an individual's action or coping mechanism fails to result in a state of perceived control. Later, DeVellis and Callahan specified that when individuals are subjected to situations characterized by uncertainty, the risk for perceived helplessness increases.

With respect to client-HCP communication's effect on uncertainty and helplessness in women with FMS, there are continued gaps in knowledge. The current study failed to detect a moderating effect of client-HCP communication between illness uncertainty and helplessness, and between helplessness and SWB. However, study limitations placed constraints on the inferences we could draw from our analyses. The inconsistencies between the narrative data and the samples' high mean score on the PHCPCS suggest there is a need for future research to evaluate the psychometric properties of the PHCPCS in women with FMS. Specific focus on examination of content validity of the PHCPCS should be pursued to discern whether the PHCPCS reflects communication priorities of women with FMS. Focus group sessions conducted with women with FMS will facilitate researchers with gaining the client's perspective of the quality of client-HCP communication. Increased clarity concerning women's communication priorities when they seek care for FMS will assist with refinement of the

items of the PHCPCS to reflect the phenomenon of client-HCP communication in women with FMS.

Additionally, due to the potential for change in the perception of client-HCP communication over time, test-retest reliability of the PHCPCS in women with FMS should be determined. Also, in keeping with Mishel's (1990) RUIT, future research is needed to re-examine the predictive models in the current study within a longitudinal design to evaluate changes over time in the appraisal of illness uncertainty and its correlates.

Despite the study's limitations, the findings from the current study provide useful information for clinical practice. While it may not be feasible to ameliorate the uncertainty of FMS, clinical practice interventions focused on empowering women with knowledge concerning FMS and strategies to control the multiple symptoms of FMS may facilitate positive coping skills, decrease sense of helplessness, and improve women's SWB. The narrative data from the current study suggest there are several clinical interventions that can be implemented by a HCP to decrease a sense of helplessness in women with FMS.

Conceivably, a HCP's acknowledgement of a client's symptoms is a starting point for decreasing uncertainty and the associated sense of helplessness that ensues from having an ambiguous illness. Another potential strategy for decreasing uncertainty and the associated helplessness consists of HCP's provision of accurate, updated information to clients concerning FMS and the potential treatments. Asbring and Narvanen (2004) reported that women with FMS seek knowledge about illness to decrease their sense of helplessness. Given there is evidence that complimentary alternative therapies improve

physical and PWB in women with FMS, a HCP's willingness to explore the use of alternative therapies in women with FMS may be a fruitful avenue for empowering women with FMS (Hardy-Pickering et al., 2007). Lastly, the gap in knowledge concerning the effect of client-HCP communication on illness uncertainty, helplessness, and SWB in women with FMS indicates there is a need to continue research efforts in this particular area to develop a strong evidence base for clinical practice. Opportunities for improving women's ability to cope with the uncertainty, pain, and multiple co-morbidities of FMS through positive client-HCP communication are promising.

Table 1*Socio-demographic Characteristics of the Sample (n = 138)*

Characteristics	n	(Percentage)
-		
Ethnicity		
Caucasian	128	(92.8%)
African American	3	(2.2%)
Asian	2	(1.4%)
Other	2	(1.4%)
Educational level completed		
High school	34	(24.6%)
2 years of college	25	(18.1%)
4 years of college	42	(30.4%)
Graduate school	35	(25.4%)
Employment status		
Employed	56	(40.6%)
Unemployed	82	(59.4%)
Disability income for FMS		
Yes	25	(18.1%)
No	108	(78.3%)
Duration of illness		
Less than 5 years	16	(12.0%)
5 to 10 years	35	(25.0%)
Greater than 10 years	87	(63.0%)
Healthcare Provider		
Primary Care Physician	78	(56.5%)
Rheumatologist	28	(20.3%)
Chiropractor	5	(3.6%)
Nurse Practitioner	2	(1.4%)
Other	23	(16.7%)
-		

**Note: Not all participants reported data*

Table 2

Summary of Pearson Correlations (r), Means and Standard Deviations for Scores on the GWBS, MUIS-C, RAI Helplessness Subscale, Pain Severity, FIQR, Illness Duration, and PHCPCS among women with FMS (n = 138)

Measure	1	2	3	4	5	6	7
1. GWBS	-						
2. MUIS-C	-.43*	-					
3. Helplessness	-.63*	.59*	-				
4. Pain Severity	-.46*	.36*	.53*	-			
5. FIQR	-.61*	.40*	.71*	.68*	-		
6. Duration	-.13	-.09	-.19*	-.18*	.00	-	
7. PHCPCS	.24*	-.51*	-.17*	-.09	-.19*	.07	-
M	48.72	70.02	17.46	6.58	60.58	17.43	64.11
SD	18.54	14.77	4.26	1.84	16.18	13.92	16.67

Note. * $p < 0.05$ for all values with an asterisk

Table 3

Summary of Regression Results for the Conditional Indirect Effect of Illness Uncertainty on SWB through Helplessness (n=138)

Predictor	<i>B</i>	SE	<i>P</i>
Mediator helplessness regressed on predictors			
Illness uncertainty (<i>a</i>)	.10	.02	$p < 0.001^*$
Functional Status	.15	.02	$p < 0.001^*$
Pain Severity	-.03	.20	$p = 0.893$
Illness Duration	-.05	.02	$p = 0.016^*$
Dependent variable subjective well-being (SWB) regressed on predictors			
Illness uncertainty (<i>c</i>)	-.26	.12	$p = 0.018^*$
Helplessness (<i>b</i>)	-1.44	.55	$p = 0.010^*$
Functional Status	-.36	.15	$p = 0.018^*$
Pain Severity	-.34	1.08	$p = 0.752$
Illness Duration	.07	.11	$p = 0.543$
Illness uncertainty (<i>c'</i>)	-.12	.12	$p = 0.332$

Notes: $*p < 0.05$ for all values with an asterisk.

Unstandardized regression coefficients are reported. Overall $R^2 = .46^*$

(*a*) denotes Path a; (*b*) denotes Path b; (*c*) denotes Path c; and (*c'*) denotes path *c'*

Table 4

Summary of Regression Results for the Interaction Effect of Client-HCP Communication and Illness Uncertainty on Helplessness and the Interaction Effect of Client-HCP Communication and Helplessness on SWB (n=138)

Predictor	<i>B</i>	SE	<i>t</i>	<i>P</i>
Mediator helplessness regressed on predictors				
Illness uncertainty (<i>a</i>)	.11	.02	4.89	$p < 0.0001^*$
Client-HCP Com (<i>a1</i>)	.05	.01	2.60	$p = 0.011^*$
Com (<i>Inter I</i>)	.00	.00	0.06	$p = 0.955$
Functional Status	.11	.02	4.99	$p < 0.0001^*$
Pain Severity	.15	.21	0.70	$p = 0.487$
Illness Duration	-.01	.02	-0.72	$p = 0.476$
Dependent variable subjective well-being (SWB) regressed on predictors				
Illness uncertainty (<i>c'</i>)	-.11	.15	-0.72	$p = 0.471$
Client-HCP Com (<i>b1</i>)	.15	.12	1.26	$p = 0.210$
Com (<i>Inter I</i>)	.01	.01	0.57	$p = 0.571$
Helplessness (<i>b</i>)	-1.49	.60	-2.53	$p = 0.013^*$
Com (<i>Inter II</i>)	.02	.03	0.51	$p = 0.609$
Functional Status	-.22	.14	-1.56	$p = 0.124$
Pain Severity	-.69	1.16	-0.59	$p = 0.556$
Illness Duration	-.03	.10	-0.28	$p = 0.783$

Notes: $*p < 0.05$ for all values with an asterisk.

Unstandardized regression coefficients are reported.

(*a*) denotes Path a; (*a1*) denotes path a1; (*Inter I*) denotes Client-HCP Com x Illness Uncertainty; (*b*) denotes Path b; (*c'*) denotes Path c'; (*Inter II*) denotes Client-HCP Com x helplessness.

CHAPTER IV
EVALUATION OF THE PATIENT-HEALTHCARE PROVIDER COMMUNICATION
SCALE IN WOMEN WITH FIBROMYALGIA SYNDROME

The purpose of this study was to evaluate the psychometric properties of the Patient-Healthcare Provider Communication Scale (PHCPCS) (Salt et al., 2012) in women with Fibromyalgia Syndrome (FMS). FMS is an idiopathic, chronic pain disorder that affects approximately 10 million people in the United States (US) and an estimated 2% to 6% of the population worldwide. While FMS is most prevalent in middle-aged women, it is known to occur in men and children (National Fibromyalgia and Chronic Pain Association [NFMCPA], 2014).

Widespread muscle and joint pain are the primary symptoms of FMS. Additionally, persons with FMS experience multiple comorbidities that remit and exacerbate in unpredictable patterns. Insomnia, difficulty with cognition, extreme fatigue, migraines, irritable bowel syndrome, anxiety, and depression are among the vast range of conditions and symptoms associated with FMS (Wierwille, 2012; Wolfe et al., 1990; Wolfe et al., 2010).

There are major gaps in healthcare for persons with FMS. The management of FMS is limited to early detection and symptom control due to its unknown etiology and subsequent lack of primary prevention strategies (Bernard et al., 2000). However, there are no objective data to diagnose FMS and there is little evidence of efficacious treatment

(Wierwille, 2012). Furthermore, because the etiology is unknown and there is absence of standardized diagnostic criteria, FMS has been viewed suspiciously by healthcare providers (HCPs) (Briones-Vozmediano et al., 2013; Grob, 2011; Wolfe, 2009).

The preponderance of the FMS qualitative literature indicates the quality of communication between women with FMS and their HCPs is impaired. Specifically, studies have found the ambiguous nature of FMS has contributed to the communication challenges encountered by clients and their HCPs (Dow et al., 2012; Egeli et al., 2008; Briones-Vozmediano et al., 2013; Hayes et al., 2010; Lempp et al., 2009; Schaefer, 2005; Thorne et al., 2004). Participants' narratives reveal that a poor quality of client-HCP communication influences adjustment to illness in women with FMS (Lempp et al., 2009; Madden & Sim, 2006; Schoofs et al., 2004; Thorne et al., 2004).

Client-HCP communication is conceptually defined as the client's perception of the exchange of information with their HCP (Charlton et al., 2008). Charlton et al. suggest that HCPs use client-centered communication to promote a mutual exchange of ideas with their client. This collaborative approach entails a primary focus on the client's health goals. Positive health outcomes associated with client-centered communication include, improved client satisfaction, increased adherence to treatment regimens, and perceived control over illness (Charlton et al, 2008; Suarez-Almazor, 2004; van Dulmen & Bensing, 2002).

To our knowledge, there are no studies that have focused on client-HCP communication as an outcome measure or have used client-HCP communication as an intervention for women with FMS. A plausible rationale for this dearth of research is due to the lack of a psychometrically sound instrument to measure the quality of client-HCP

communication in women with FMS. Although there are no self-report scales specifically designed to measure client-HCP communication in women with FMS, the literature indicates the PHCPCS (Salt et al., 2012) may be a suitable instrument to measure the client's perception of the quality of client-HCP communication.

In addition to the PHCPCS demonstrating strong internal consistency reliability in a sample of persons with rheumatoid arthritis (RA), the PHCPCS is unique in that it was developed from the perspective of clients with RA concerning their communication priorities (Salt et al., 2012). Commonalities shared by persons with RA and FMS provide further indication for the PHCPCS as a potential measure for client-HCP communication in women with FMS. The literature indicates musculoskeletal pain is a prevalent symptom of RA and FMS and that both medical populations perceive client-HCP communication as an important component of quality healthcare (Briones-Vozmediano, et al., 2013; Dow et al., 2012; Haugli et al., 2004; Thorne et al., 2004).

The specific aims of this study were to (1) measure the quality of client-health care provider communication in women with FMS using the PHCPCS; (2) examine the internal consistency reliability of the PHCPCS when used with this population; and (3) examine the dimensionality of the PHCPCS.

Methods

Design and Sample

The baseline data for this cross-sectional study came from a previous study that examined the relationships among client-HCP communication, illness uncertainty, helplessness, and subjective well-being (SWB) in women with FMS. The data from the parent study were used to assess the quality of client-HCP communication and evaluate

the psychometric properties of the PHCPCS in a sample of women with FMS. The parent study is presented in Chapter Three of this dissertation.

The baseline data were collected from women with FMS in a community located in the southern region of the United States (US) and nationally from online fibromyalgia support groups. One hundred and fifty respondents volunteered to participate in the parent study and indicated that they met the study's inclusion criteria. The participants had to (a) be female, (b) self-identify as having a confirmed diagnosis of FMS, (c) be at least 18 years of age, and (d) be proficient in English in order to be included in the study.

The majority of the data were collected from electronic health surveys that were completed by the participants using Research Electronic Data Capture (REDCap), a secure, web-based application designed to support data capture for research studies (Harris et al., 2009). A smaller percentage of the data were obtained from participants' completed pencil and paper surveys that were returned to the researchers via US postal mail in a self-addressed, postage paid envelope that was provided for the participants in the survey packet.

Of the 158 participants enrolled in the parent study, 141 participants returned completed surveys. Of the 141 returned surveys, three were excluded from the analysis due to missing age and gender data on the demographic questionnaire. Thus, a total of 138 women with FMS composed the sample for the current study.

Measures

The current study involved collecting data from a demographic questionnaire and the Patient Health Care Provider Communication Scale (PHCPCS) (Salt et al., 2012).

Demographic questionnaire. The socio-demographic data collected included participants' age, gender, ethnic background, educational level, employment, disability compensation, duration of FMS symptoms, year of diagnosis, and type of HCP used for management of FMS.

The quality of client-HCP communication. The PHCPCS (Salt et al., 2012) is a 21-item self-report questionnaire that was developed from a sample of RA patients. Salt et al. reported that the scale's 21 items reflect two dimensions of patient-HCP communication. The first dimension, quality communication is comprised of 17 items and the second dimension, negative patient-HCP communication is comprised of 4 items. Each item is rated on a 4-point Likert scale of (1 = *not at all*, 2 = *somewhat like*, 3 = *much like*, and 4 = *very much like*). During development of the PHCPCS, feedback from rheumatologists, a behavioral scientist and a nurse researcher on the relevance of the scale items to patient-HCP communication in RA patients provided support for content validity. Additionally, face validity for the PHCPCS was established based on the RA patient's opinions on readability and comprehension. The developers indicated that the wording of the PHCPCS was adjusted to ensure a sixth grade reading level (Salt et al., 2012).

Salt and colleagues (2012) found evidence for construct validity of the PHCPCS by demonstrating that the PHCPCS total scores and subscale scores correlated with the Perceived Involvement in Care Scale (PICS) (Lerman et al., 1990). The PICS is a general measure of patients' perceptions of doctor-patient communication during a healthcare consultation. However, researchers have noted limitations of the PICS. The major limitation discussed is that the scale does not assess the patient's perception of specific

physician behaviors, such as when a physician behaves in an impatient or rude manner (Smith et al., 2006). Salt et al. (2012) concurred with this limitation of the PICS and reported that there was a need to develop a scale that directly measured the phenomenon of the patient's perception of patient-HCP communication.

The PHCPCS demonstrated strong internal consistency reliability in the RA population studied by Salt et al. (2012). In the study of 150 RA patients, the total PHCPCS had a Cronbach's alpha of 0.89. Alphas for the subscales, Quality Communication and Negative Patient-HCP Communication were reported as 0.94 and 0.73 respectively (Salt et al., 2102).

Procedure

The study protocol of the parent study was reviewed and approved by the institutional review board of a southern metropolitan university. Data were analyzed using the IBM Statistical Package for the Social Sciences (SPSS), Windows Version 20.0. First, the data were summarized and explored. Overall, the missing values were random. It was determined that each variable had less than 3% missing data and there was less than 5% missing data on the PHCPCS. Prior to performing any statistical analyses, the negatively worded items of the PHCPCS were recoded. Descriptive statistics were conducted for the entire sample with means, medians, standard deviations, and ranges for the PHCPCS and frequencies and percentages for all categorical variables.

Principle component analysis (PCA) with direct Oblimin rotation was used to evaluate the dimensionality of the 21 item PHCPCS and determine if elimination of item(s) would improve the overall measure of the quality of client-HCP communication. In terms of the sample size requirement for PCA, we used Tinsley and Tinsley's (1987)

recommendation of 5 to 10 participants per scale item. In addition, several statistical tests were conducted to assess the suitability of the data for PCA. The Kaiser-Meyer-Olkin (KMO) index of sampling adequacy (Kaiser, 1970) and Bartlett's test of sphericity (Bartlett, 1954) were calculated. The correlation matrix was also examined for evidence of coefficients greater than 0.30 to determine strength of the relationship among the items on the PHCPCS (Tabachnick & Fidell, 2007).

The eigenvalues, Catell's (1966) Scree test, and amount of variance explained by the factors were analyzed to determine the number of factors to retain and rotate using direct Oblimin rotation. Factors that had an eigenvalue greater than 1 and were positioned above the elbow on the Scree plot were retained for rotation (Tabachnick & Fidell, 2007). The cut point of 0.30 or greater was used to identify factor loadings defining a given factor (Thurstone, 1947). The internal consistency reliability of the PHCPCS total scale and its subscales was assessed using Cronbach's alpha.

Results

Sample Characteristics

The participants in the sample ($n = 138$) were primarily Caucasian (91%), with a mean age of 53.2 years (standard deviation (SD) = 12.4). More than three fourths of the participants had a college degree or higher. Fifty-nine percent of the participants were unemployed and only 18% reported receiving disability related compensation. The average duration of illness was 17.4 years with a range from 6 months to 60 years. The vast majority (88%) had experienced symptoms greater than 5 years. Only 55% reported receiving a diagnosis of FMS within the past 10 years. A substantial percentage (77%) reported receiving care for their FMS from a physician. The remainder reported receiving

care from other healthcare specialists and complimentary therapy providers (See Table 5 for summary of the socio-demographic characteristics).

The Quality of Client-HCP Communication

The PHCPCS total scale score, obtained by adding each participant's responses on a 4 point Likert Scale, indicated the degree to which the individuals rated the quality of client-HCP communication. The possible score on the PHCPCS has a range of 21 (participant perceives a low quality of client-HCP communication) to 84 (participant perceives a high quality of client-HCP communication). The distribution of scores for the PHCPCS were flat and negatively skewed indicating the majority of the participants perceived a high quality of client-HCP communication. The samples' mean score on the PHCPCS was 64.11 ($SD = 16.67$).

Psychometric Testing of the PHCPCS

Internal Consistency Reliability. Cronbach's alpha was 0.97, indicating strong internal consistency reliability for the 21 item PHCPCS. Alphas for the subscales, Quality Communication and Negative Patient-HCP Communication were 0.98 and 0.78 respectively. The inter-item correlations for the total PHCPCS were all positive indicating the negatively worded items 3, 4, 6, and 20 were correctly reverse scored. The mean inter-item correlation value was 0.61 with values ranging from 0.28 to 0.90. Item 14 '*Presents me with all of my treatment options*' had the lowest inter-item correlation with item 20 '*Have avoided telling my healthcare provider about my health because I'm afraid of what they will think or say*'. However, all corrected item total correlations were above 0.30, and ranged from 0.42 to 0.98. Deletion of item 14 improved the alpha only slightly to 0.98, so it was retained. Deletion of item 14 revealed an alpha of 0.80. Because

deletion of item 14 failed to improve the Cronbach's alpha for the total scale of the PHCPCS, this item was also retained.

Dimensionality. The study's sample size ($n = 138$) yielded approximately 6.6 participants per item on the PHCPCS, exceeding the minimum ratio of 5 cases for each of the scale items (Tinsley & Tinsley, 1987). Inspection of the correlation matrix revealed the presence of many coefficients of 0.61 and above, indicating medium to large correlations among the majority of the items of the PHCPCS. The KMO value, 0.96 and significant Bartlett's test of Sphericity ($p < 0.001$) provided additional evidence that the data was suitable for PCA (Tabachnick & Fidell, 2007). Two components were identified with eigenvalues exceeding 1. Support for the retention of two components was illustrated in the Scree plot with a clear break after the second component.

When the component matrix was examined, 17 items loaded strongly on the first component and four items double loaded on components 1 and 2. However, Oblimin rotation of the two-component solution revealed the presence of a simple structure of the PHCPCS. There were no double loadings. Both components showed primary loadings with items loaded substantially on only one component. Oblimin rotation was chosen as the rotation method based on the expectation of inter-correlation among the components. Specifically, there were 16 primary loadings on component 1 with a range of 0.73 to 0.95 and three primary loadings on component 2 with a range of 0.80 to 0.82. Because there were no items with a component loading less than 0.40 and none double loaded, all of the original 21 PHCPCS items were retained. The two-component solution explained 70% of the variance of the PHCPCS with component 1 contributing 63.9% and component 2 contributing 6.1% of the variance. Further analysis of the items revealed positive

communication items loaded strongly on Component 1 and negative communication items loaded strongly on Component 2. Additionally, there was a large positive correlation ($r = .63$) between the two components indicating there is shared variance between the two dimensions of the PHCPCS (See Table 6 for the PCA Oblimin rotation results).

Discussion

Summary of Main Findings

In this study we tested the psychometric properties of the PHCPCS in a sample of women with FMS. In reference to reliability, our results demonstrated that among women with FMS, the total scale of the PHCPCS had strong internal consistency reliability. For the subscales, the Quality Communication subscale exhibited strong internal consistency reliability and the Negative Communication subscale of the PHCPCS had adequate internal consistency reliability. The PHCPCS total scale and subscales had stronger Cronbach's alphas in the current sample than the alphas previously reported by Salt and colleagues (2012) in a sample of patients with RA. Additionally, the corrected item-total correlations were all above 0.40, which provided evidence that each of the items contributed to the measure of the quality of client-HCP communication.

In our principle components analysis, two dimensions emerged; quality communication and negative communication. The first component explained 63.9% of the variance in the PHCPCS and the second component explained 6.1% of the scale's variance. Our interpretation of the two components was consistent with the scale developers' (Salt et al., 2012) findings, with positive communication items loading strongly on Component 1 and negative communication items loading strongly on

Component 2. Additionally, as expected, based on findings of Salt et al. (2012) research, there was a large positive correlation ($r = .63$) between the two components indicating there is shared variance between the two dimensions of the PHCPCS.

Overall, the data indicate the PHCPCS is a reliable measure of the quality of communication in women with FMS. While our PCA results are congruent with those of Salt and Colleagues (2012), the high internal consistency reliability of the total PHCPCS and the lower Cronbach's alpha of 0.78 for the Negative Communication subscale indicates the PHCPCS may be more useful as a uni-dimensional measure of the quality of client-HCP communication in women with FMS. Further indication of a single dimensional structure of the PHCPCS was noted with the number of primary loadings on the second component, negative communication. Additionally, there were only four items that loaded on the second component and only three of the four were primary loadings.

Limitations

The majority of the participants reported receiving healthcare for their FMS from a physician. Thus, our results concerning the participants' perceptions of quality of client-HCP communication does not clearly represent women's perceptions of communication with other types of HCPS. Additionally, the majority of the participants were Caucasian women with a college education. However, women with less education were represented in the current study, as well as women from other ethnic backgrounds. We also recognize that the sample size was on the lower acceptable range of Tinsley and Tinsley's (1987) sample recommendation for principle component analysis. Therefore, further psychometric testing of the PHCPCS should be done in a larger sample size. Another limitation was that we were limited in comparing our results of the psychometric testing

of the PHCPCS to those of Salt et al. (2012). Thus, future research is needed to assess test-retest reliability of the PHCPCS in women with FMS. It is possible that the PHCPCS may be sensitive to change over time (Salt et al., 2012).

Conclusion

To our knowledge, this is the first study that has evaluated the psychometric properties of a communication instrument in women with FMS. The qualitative literature reveals client-HCP communication is a critical problem for women with FMS. Researchers report women perceive that HCPs do not believe in FMS, are unwilling to listen to their client's healthcare concerns, discuss treatment options for FMS, and provide referrals to providers from other healthcare disciplines (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Shuster et al., 2009; Thorne et al., 2004). Thus, the perceived high quality of client-HCP communication as measured by the PHCPCS in the sample of women with FMS was not anticipated. However, the samples' high mean score on the PHCPCS ($M = 64.11$, $SD = 16.67$) is an uplifting finding as it indicates the participants perceived positive interactions and communication with their HCP.

In summary, a reliable and valid communication assessment tool is needed in clinical practice to provide feedback to HCPs concerning FMS clients' communication priorities. Our findings indicate the PHCPCS may be a useful instrument in clinical practice to measure the FMS client's perception of the quality of communication with their HCP. However, because the PHCPCS was developed from the perspective of persons with RA, there is a need to evaluate whether the PHCPCS reflects the phenomenon of client-HCP communication in women with FMS. Future research using qualitative inquiry to understand the perceptions of the quality of client-HCP

communication in women with FMS will assist researchers with identifying whether the PHCPCS captures certain attributes of client-HCP communication that are important for women with FMS.

There are several ways the PHCPCS may benefit women in the future with FMS. If evidence of content validity exists after further study of the PHCPCS in women with FMS, researchers may consider using the PHCPCS as an outcome measure in intervention studies. Additionally, the PHCPCS may provide feedback to HCPs concerning their communication with women with FMS. Importantly, an increased awareness of the communication priorities of women with FMS may assist HCPs with establishing therapeutic client-HCP relationships and identifying effective strategies to assist women's adjustment to FMS.

Table 5*Socio-demographic Characteristics of the Sample (n = 138)*

Characteristic	n	(Percentage)
-		
Ethnicity		
Caucasian	128	(92.8%)
African American	3	(2.2%)
Asian	2	(1.4%)
Other	2	(1.4%)
Educational level completed		
High School	34	(24.6%)
2 years of college	25	(18.1%)
4 years of college	42	(30.4%)
Graduate school	35	(25.4%)
Employment status		
Employed	56	(40.6%)
Unemployed	82	(59.4%)
Disability income for FMS		
Yes	25	(18.1%)
No	108	(78.3%)
Duration of illness		
Less than 5 years	16	(12.0%)
5 to 10 years	35	(25.0%)
Greater than 10 years	87	(63.0%)
Healthcare Provider		
Primary Care Physician	78	(56.5%)
Rheumatologist	28	(20.3%)
Chiropractor	5	(3.6%)
Nurse Practitioner	2	(1.4%)
Other	23	(16.7%)
-		

**Note: Not all participants reported data.*

Table 6

Principle Component Analysis with Oblimin Rotation of Two Components for the Patient Healthcare Provider Communication Scale (n= 138)

Item	Description	Component	
		I	II
10.	Tries to find answers to my health problems.	0.95	
8.	Takes my health concerns seriously.	0.90	
16.	Explains my health condition in detail.	0.89	
9.	Pays attention to what I say about my health.	0.89	
2.	Asks me questions so that he/she understands my health problems.	0.89	
14.	Presents me with all of the treatment options.	0.88	
7.	Is concerned about my understanding of my health.	0.87	
18.	Approaches my treatment with a positive attitude.	0.84	
15.	Is knowledgeable about my health condition.	0.84	
1.	Answers my questions about my health.	0.83	
21.	Am able to make health related decisions because of the information provided by my healthcare provider.	0.81	
12.	Is honest with me about my health.	0.80	
5.	Understands my concerns about my health condition.	0.79	
11.	Is patient.	0.77	
17.	Treats me as she or he would want to be treated.	0.78	
13.	Treats me with kindness.	0.73	
19.	Feel comfortable about telling my healthcare provider about my health concerns.	0.60	
3.	Is in a hurry when he or she is seeing me.		0.82
6.	Has been rude to me.		0.81
4.	Makes me feel that I am bothering him/her with my medical concerns.		0.80
20.	Have avoided telling my healthcare provider about my health because I am afraid of what they will think or say.		0.57

^a Component I = Quality communication; Component II = Negative Communication

^b Columns represent component loadings. Items with loadings greater than 0.70 for Components I and II are boldface.

CHAPTER V
SYNTHESIS OF THE DISSERTATION FINDINGS

Summary of Main Findings

This dissertation research fulfilled a critical need to evaluate the relevance of client-healthcare provider (HCP) communication to the appraisal of illness uncertainty in women with FMS. As discussed previously in the dissertation, multiple qualitative studies have shown that illness uncertainty is a salient experience of women with FMS. Additionally, the literature indicates communication between clients and their HCPs influences illness uncertainty in women with FMS (Dow et al., 2012; Egeli et al., 2008; Lempp et al., 2009; Madden & Sim, 2006; Sallinen et al., 2011; Schaefer, 2005; Schoofs et al., 2004; Shuster et al., 2009; Thorne et al., 2004). However, there is a lack of empirical evidence concerning the effect of client-HCP communication on illness uncertainty and emotional outcomes in women with FMS. This gap in knowledge was the impetus for the dissertation research.

A modification of Mishel's (1990) reconceptualized uncertainty in illness theory (RUIT) was used as the conceptual framework to guide the dissertation research. Client-HCP communication was conceptualized as a resource for women with FMS that facilitates women's adjustment to chronic uncertainty. A mixed-methods design was employed to increase clarity concerning the relevance of client-HCP communication to the appraisal of illness uncertainty in women with FMS. Importantly, the data obtained

from qualitative and quantitative inquiry were complimentary and thus enhanced validity of the dissertation research findings.

The principle findings of this dissertation research indicate (a) illness uncertainty is a risk factor that increases women's vulnerability to the perception of helplessness and poor SWB; (b) helplessness influences the impact of uncertainty on SWB in women with FMS; (c) multiple factors contribute to the emotional anguish experienced by women living with FMS; (d) further study is needed to determine whether the patient-healthcare provider communication scale (PHCPCS) is a valid measure of the quality of client-HCP communication in women with FMS; and (e) there are gaps in knowledge concerning the effect of client-HCP communication on illness uncertainty, helplessness, and SWB in women with FMS.

The qualitative study showed that the cognitive stressor, illness uncertainty, was at the forefront of the women's distress. Participants' narratives revealed that a continual state of uncertainty was experienced from living with an illness that was invisible to society and thus misunderstood by HCPs, family, friends and co-workers. Each of the women expressed in their own ways that a sense of helplessness evolved from living with an unexplained illness, relentless pain, and multiple, unpredictable symptoms. Additionally, dismissal by HCPs was a prevalent experience among the sample of women with FMS that compounded their uncertainty and sense of powerlessness.

Importantly, the data obtained from individual interviews conducted with the participants in the qualitative pilot study provided insight concerning the multiple factors that contribute to perceived uncertainty, helplessness, and poor SWB in women with FMS. Indeed, lack of knowledge concerning the etiology of FMS, cause of symptoms,

treatment, and prognosis presented as the initial sources of uncertainty for all three women in the qualitative pilot study. For each of these women, the mysteriousness of FMS exacerbated their apprehension and led to their quest for a HCP who would acknowledge their illness and provide treatment for their symptoms. However, negative interactions with HCPs and lack of support from significant others contributed to the women's uncertainty and led to feelings of insecurity and helplessness. Each of the women expressed that they felt as if they were "going crazy" due to the invisibility of FMS and the lack of validation of their illness.

Loss also stood out as a salient experience of the participants in the qualitative pilot study and an additional factor that contributed to the women's decreased outlook on life. The theme, "Losing" emerged from the women's descriptions of suffering from loss of career, interpersonal relationships, and ability to maintain pre-illness modes of function. Alteration in physical and mental function interfered with their daily home routines, ability to perform at work, and ability to enjoy life with family and friends. The women articulated how severe despondency was experienced from living with unpredictable pain, impaired function, loss of supportive relationships, and feelings of helplessness.

Yet the women's stories revealed that hope was eventually experienced. The themes, "My Best Day" and "Hope: I Can Do This" emerged from the women's descriptions of moments in their life in which a HCP or a close relation provided them with encouragement and hope. The women shared that positive communication with HCPs and supportive interpersonal relationships facilitated a sense of optimism that they could cope with the debilitating symptoms of FMS.

Quantitative inquiry yielded pertinent information concerning how illness uncertainty, helplessness, functional status, pain, and SWB are related in women with FMS. The empirical data were in concert with the qualitative findings, demonstrating that uncertainty is risk factor for emotional distress in women with FMS. The multiple regression results presented in Chapter Three revealed a statistically significant relationship between the predictor variable, illness uncertainty and the outcome variable SWB when controlling for functional status, pain severity, and illness duration. Additionally, both helplessness and functional status were uniquely related to poor SWB, with increased distress associated with perceived helplessness and impairment in function. The overall regression model in the mediation testing explained 46% of the variance in SWB. Together, the regression model and the findings from the qualitative pilot study suggest multiple factors influence emotional outcomes in women with FMS.

However, the most noteworthy finding of the quantitative study presented in Chapter Three involved the central role of helplessness in mediating the relationship between uncertainty and SWB. The statistical results of the mediation testing demonstrated the effects of uncertainty on the participant's SWB were indirect and mediated through helplessness. This specific finding clarifies that the appraisal of uncertainty in women with FMS is strongly affected by perceived helplessness.

The dissertation findings extend the body of literature on uncertainty in women with FMS. While previous research indicates perceived helplessness and functional status are predictors of depression in women with FMS (Nicassio et al., 1999; Palomino et al., 2007), there is minimal evidence concerning how helplessness, uncertainty, and emotional outcomes are related. The findings of Reich and colleagues (2006) were

pivotal in providing beginning evidence that helplessness plays a key role in the appraisal of illness uncertainty in women with FMS. The quantitative findings of this dissertation research strengthen the evolving body of FMS literature. The culminating data suggest it is critical for HCPs to recognize the psychological impact of uncertainty in women with FMS. Support for this inference is found in Mishel's (1990) RUIT.

Mishel (1990) explained that the unrelenting uncertainty experienced with chronic illness is an invasive force that affects all aspects of daily life and thus creates a sense of chaos. The theorist asserted that the perceived turmoil that ensues from continual uncertainty impedes the individual's ability to assign meaning to their illness and often results in emotional distress (Mishel & Clayton, 2008). However, Mishel (1990) emphasized that it is possible for individuals with chronic illness to adjust to the uncertainty in their lives. Positive client-HCP communication that encourages chronically ill individuals to consider alternatives and choices in their life helps the individual to shift their view of uncertainty from a catastrophic force to a natural way of life. This conceptualization involves the individual's acknowledgement that uncertainty is an unavoidable part of their life. In gaining this realization, aversive thoughts and behaviors associated with helplessness are abandoned (Mishel, 1990).

In regard to the dissertation findings concerning distinct relationships among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS, there was a lack of empirical evidence to support client-HCP communication as a moderator of the relationships between illness uncertainty and helplessness, and between helplessness and SWB in this sample of women with FMS. However, the inconsistencies between the samples' mean score on the PHCPCS and the majority of the participant's

written responses to the question, *'When I visit my HCP for my FMS, I wish my HCP would'* placed constraints on the inferences that could be drawn from the dissertation concerning the effect of client-HCP on the appraisal of uncertainty in women with FMS.

The samples' high mean score on the PHCPCS reflected a high quality of client-HCP communication and the narrative data showed that the majority of the participants had experienced negative communication encounters with HCPs. While the samples' high mean score on the PHCPCS was an optimistic finding, many of the participants described their desire for a HCP who would actively listen to their voices. Another prevalent finding was that the women's narratives reflected that they wished for a HCP who would believe in their symptoms and their personal appraisal of their condition. Additionally, a majority of the participants' written responses reflected their wish for more knowledge from their HCP. Thus, the themes, "Listen and Believe" and "Provide Me with More Knowledge" emerged from the narrative data in the correlational study.

The discrepancies in the communication data concerning the participant's perceived quality of communication with their HCP suggests that the PHCPCS was deficient in capturing the phenomenon of client-HCP communication in women with FMS. However, analysis of the narrative data revealed that many of the participant's written responses reflected a culmination of experiences with HCPs. Based on this finding, it was speculated that the samples' high mean score on the PHCPCS represented the participant's perceptions of communication with a HCP in which they had spent many years searching. Previous studies have documented that women with FMS engage in multiple consultations with HCPs over a lifetime to legitimize their illness and assist their ability to manage FMS (Annemans et al., 2009; Brionnes, Vives-Cases et al., 2013;

Dow et al., 2012; Hayes et al., 2010; Lempp et al., 2009; Madden & Sim, 2006; Perrot et al., 2012; Schaefer, 2005; Thorne et al., 2004).

In terms of the validity of the PHCPCS as a measure of the quality of client-HCP communication in women with FMS, it would be erroneous to formulate a conclusion about the PHCPCS's content validity based on the findings of this dissertation. As discussed previously, this dissertation research was the first to use the PHCPCS to measure client-HCP communication in women with FMS. Therefore, there was no data to compare the performance of the PHCPCS in the dissertation research. The findings from the psychometric evaluation of the PHCPCS presented in Chapter Four suggest that the PHCPCS is a reliable measure of the quality of communication in women with FMS. In addition, results from the principle component's analysis presented in Chapter Four suggest that the PHCPCS is most useful as a uni-dimensional measure of client-HCP communication in women with FMS.

However, the comprehensive data concerning the PHCPCS in the dissertation research indicates further study is needed to evaluate whether the PHCPCS reflects the core components of communication that are of high importance to women with FMS. Evaluation of the specific items on the PHCPCS presented in Chapter Three indicated there are no items on the PHCPCS that contain the words listen or believe. Additionally, it was found that there is only one item on the PHCPCS that addresses the participant's perception of their ability to make a decision about their healthcare based on the quality of a HCP's communication. This content is reflected in item 21 of the PHCPCS, '*Am able to make health-related decisions because of the information provided by my healthcare provider*'. Interestingly, item 21 was among the lower scoring items on the

PHCPCS in the correlational study. Based on this evidence, it could be argued that the lack of items on the PHCPCS dedicated to quality components of HCP communication such as a HCP's listening and believing, as well as a HCP's communication that empowers decision making may have accounted for the correlational study's lack of support for client-HCP communication as a moderator between illness uncertainty and helplessness and between helplessness and SWB.

In summary, although the dissertation research found there are gaps in knowledge concerning distinct relationships among client-HCP communication, illness uncertainty, helplessness, and SWB, the overall findings of this dissertation research shed light on the relevance of client-HCP communication to the appraisal of uncertainty in women with FMS. Importantly, the themes that emerged from the participants' narratives from the qualitative pilot study and the majority of the participants' written responses from the quantitative study were congruent with Mishel's (1990) RUIT. Together, the narrative data suggest that there are specific attributes of a HCP's communication that affect the appraisal of uncertainty and perceived helplessness in women with FMS. Considering the quantitative study presented in Chapter Three provided evidence that helplessness mediated the relationships between illness uncertainty and SWB in the sample of 138 women with FMS, the narrative findings of the dissertation research are especially important.

The participants in qualitative study and the quantitative study expressed that they sought and wished for a HCP that would actively listen to their health concerns, provide validation of their symptoms, and thus legitimize their illness. Additionally, the narrative findings suggest that knowledge from HCPs has the potential to decrease uncertainty and

empower women's ability to self-manage their symptoms of FMS. Thus, the dissertation findings suggest that client-HCP communication has the potential to assist women with assigning meaning to their illness experience, consider alternatives and choices in their life, and decrease perceived helplessness.

Limitations

A major limitation of the dissertation research concerned the instrument that was used to measure the quality of communication in women with FMS. As discussed previously, there are no existing instruments that have been specifically designed to measure the quality of client-HCP communication in women with FMS. The PHCPCS is a relatively new instrument and was developed from the perspective of rheumatoid arthritis (RA) patients concerning the RA client's communication priorities with HCPs (Salt et al., 2102). Therefore, future research using qualitative inquiry is needed to assess the appropriateness of the core themes of the PHCPCS for measuring the quality of client-HCP communication in women with FMS. Once content validity of the PHCPCS is established in women with FMS, test-retest reliability needs to be evaluated to discern its consistency in measuring client-HCP communication over time.

The small sample size in the qualitative pilot study was another limitation. Additionally, the participants in the qualitative pilot study were from the same fibromyalgia support group. These factors limit the representativeness of the qualitative dissertation findings. Although each of the participant's participation was anonymous and confidential, it is possible that due to the purpose and nature of support groups, the participant's sharing of their experiences of living with FMS with fellow support group members in support group meetings may have influenced the responses of the

participants during the interviews. Additionally, the majority of the women participating in the dissertation research consisted of Caucasian women with a college degree.

However, other ethnic and racial groups with various education levels were represented.

Another limitation was the use of self-report for data collection in the quantitative studies. It is possible that the relationships among the constructs in the quantitative study presented in Chapter Three may have been inflated. Given the debilitating symptoms of FMS and its history as a contested illness by the medical community, it is likely that the majority of women participating in the study were those who suffered the highest impact from FMS and had encountered difficulties with client-HCP communication.

Furthermore, causal inferences concerning the direction of relationships among the study variables could not be determined. Conceivably, perceived helplessness may have preceded the perception of uncertainty in the sample of women with FMS or a primary mood disturbance may have influenced sense of helplessness and uncertainty.

The measurement of illness uncertainty and its potential correlates at only one point in time was also a limitation of the dissertation research. Mishel's (1990) theory asserts that the appraisal of uncertainty in chronic illness is a dynamic process that gradually shifts from danger to uncertainty over time. Therefore, it was recognized that the participant's perceptions of client-HCP communication, uncertainty, helplessness, functional status, and SWB in the correlational study did not reflect temporal changes perceived by the participants in these constructs. Illness duration was included as a covariate in the predictive models to examine whether illness duration would contribute to the prediction of SWB in the sample of women with FMS. However, illness duration failed to show a correlation with illness uncertainty, functional status, client-HCP

communication, and SWB. Although illness duration showed a correlation with helplessness and pain severity, the strength of the relationships were small. Furthermore, illness duration failed to contribute to the overall model in predicting SWB.

Practice Implications

Despite the limitations of the dissertation research, the qualitative findings provide support for theoretical work of Mishel (1990) and contribute to the existing body of literature by providing further insight of the complexity of FMS and increasing understanding of the lived experiences of women with FMS. In addition, the quantitative findings strengthen the evidence concerning the unique relationships among helplessness, illness uncertainty and SWB in women with FMS. The data suggest that while illness uncertainty is associated with emotional distress in women with FMS, it is the individual's perceived sense of helplessness that strongly influences the impact of illness uncertainty on SWB.

Although it may not be possible to mitigate the uncertainty experienced by women living with FMS, clinical practice interventions focused on empowering women with knowledge concerning FMS and strategies to control the multiple symptoms of FMS may facilitate positive coping skills, decrease sense of helplessness, and promote positive emotional outcomes in women with FMS. The narrative data from the current study suggest there are several communication strategies that HCPs may employ to decrease the perception of helplessness in women with FMS. Conceivably, a HCP's acknowledgement of a client's symptoms is a starting point for decreasing uncertainty, the associated sense of helplessness that ensues from having an ambiguous illness, and promoting quality client-HCP communication.

Madden and Sim (2006) found that a diagnosis of FMS contributed minimally to the women's knowledge of their illness and thus had little effect on reducing their uncertainty. The investigators reported that a FMS diagnosis failed to provide an explanation for invisible symptoms, and failed to answer the women's fundamental questions related to why they had acquired FMS, and why multiple HCPs had dismissed their symptoms. Since a diagnosis of FMS conveys minimal information, a HCP's acknowledgement of a client's symptoms helps to alleviate some of the uncertainty experienced with FMS and validates the individual's illness experience (Madden & Sim, 2006).

Providing accurate, updated information to clients concerning FMS and its potential treatments is another potential strategy for facilitating women's adjustment to uncertainty and for reducing the associated helplessness she may experience. Asbring and Narvanen (2004) reported that women with FMS seek knowledge about illness to decrease their sense of helplessness. Given there is evidence that complimentary alternative therapies improve physical and PWB in women with FMS, a HCP's willingness to explore the use of alternative therapies in women with FMS may be a fruitful avenue for empowering women with FMS (Hardy-Pickering et al., 2007). Camerini, Schultz, and Nakamoto (2012) found knowledge and empowerment had a strong effect on health outcomes in a sample of women and men with FMS. The researchers reported that the participant's acquisition of knowledge related to FMS symptoms, etiology, treatments, and management and sense of empowerment greatly influenced their perception of the impact of FMS on their daily life.

Lastly, the gaps in knowledge concerning distinct relationships among client-HCP communication, illness uncertainty, helplessness, and SWB in women with FMS indicates there is a need to continue research efforts in this particular area to develop a strong evidence base for clinical practice. Opportunities for improving women's ability to cope with the uncertainty, pain, and multiple co-morbidities of FMS through positive client-HCP communication are promising.

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CURRICULUM VITA

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Education

Ph.D in Nursing Research, Successfully Defended *November 9, 2015*
Graduation December 2015

University of Louisville School of Nursing, Louisville, KY

Master of Science in Nursing, *December 2006*

Bellarmino University School of Nursing, Louisville, KY

Bachelor of Science in Nursing, *May 1990*

Bellarmino University School of Nursing, Louisville, KY

Associate of Science in Nursing, *May 1985*

Bellarmino College School of Nursing, Louisville, KY

Professional Teaching Experience

Teaching Experience 2000-present

**Bellarmino University, Lansing School of Nursing and Health Sciences
Louisville, KY**

Didactic Teaching, 2004-present

**Bellarmino University, Pre-licensure students- traditional undergraduate
and second degree, accelerated nursing students**

N110 Introduction to Nursing (Freshman level)

N311 Health Assessment, Master Teacher (Sophomore level)

N310 Nursing Process with Ill Adults II, Medical Surgical Nursing (Junior level)

N430 Complex Health Problems, Critical Care Nursing (Senior level)

N455 Leadership (Senior level)

Clinical Teaching, 2000-present

Bellarmino University, Pre-licensure students- traditional undergraduate
N205 Foundations of Nursing (Sophomore level)
N230 Nursing Process with Ill Adults I, Medical Surgical Nursing (Sophomore level)
N311 Health Assessment- Master Teacher, Laboratory Instruction (Sophomore level)
N310 Nursing Process with Ill Adults II, Medical Surgical Nursing (Junior level)
N430 Complex Health Problems, Critical Care Nursing (Senior level)

Nursing Faculty Committee Work, 2004-present
Bellarmino University, Lansing School of Nursing & Health Sciences,
Louisville, KY

University Student Awards and Honors Committee
Program Effectiveness Committee
Admission Progression and Graduation Committee
Respiratory Faculty Search Committee

Nursing Practice Experience

Norton Hospital Suburban, Louisville, KY 1998-2006
Endoscopy, pre-procedure and post-procedure areas
Radiology, special procedure and invasive procedure areas
Ambulatory Care-outpatient services

Norton Hospital Audubon, Louisville, KY 1986-1998
Neurological Intensive Care Unit, Charge Nurse and Staff Nurse
Intensive Care Unit, Staff Nurse
Post Anesthesia Care Unit, Staff Nurse
Surgical Services- Intra-Operative Circulating Nurse
Radiology, Special and Invasive Procedure Nurse
Nutrition Support Nurse (Interprofessional Team-Nutritional Support Nurse)
Transitional Care Unit, Charge Nurse and Staff Nurse

Spectra Care, Louisville, KY
Part-time community nursing, home health visits 1994-1996

Baptist Hospital East, Louisville, KY 1985-1986
Intensive Care Unit, Staff Nurse

Hospital Awards/Honors
Better Care Nursing Award, Norton Hospital Suburban, 2005

Professional Memberships

Kentucky Nurses Association (KNA)

American Nurses Association (ANA)
Sigma Theta Tau International Honor Society of Nursing Induction, 2007
Southern Nursing Research Society (SNRS), 2014-2016

Community and Professional Service

Brain Injury Association of Kentucky (Organized fund-raising walk, 2008, 2009)

Bellarmino University Association of Nursing Students- Faculty Advisor 2007-2013

Interprofessional Faculty Panel Presentation, Bellarmine University School of Nursing & Health Sciences, Louisville, KY 2015

Presentations at Professional Meetings

Reibel, M. & Jones, H., Hager, K., Golemboski, K., Pariser, G., Lindsay, T., & Hall-Bibb, D. (2015). Education in Healthcare from the Classroom to the Community to Impact Population Health. Bellarmine University, Student Success Conference.

Reibel, M. & Pearson, D. (2014). Beyond the Pain: A Look into the Experiences of Women Living With and Seeking Treatment for Fibromyalgia. Southern Nursing Research Society 2014 Conference: San Antonio, Texas.

Reibel, M. (2010). Providing Student Feedback in the Clinical Setting. Bellarmine University, Clinical Instructor Conference.

Reibel, M. & Minton, L. (2010). Head to Toe Physical Assessment Teaching Strategy. Bellarmine University, Clinical Instructor Conference.

Reibel, M. & Lee, B. (2009). How to Grade a Care Plan. Bellarmine University, Clinical Instructor Conference.

Reibel, M. (2008). Nursing Curriculum Presentation. Bellarmine University, Clinical Instructor Conference.

Reibel, M. (2007). Pre and Post Clinical Conference Teaching Strategies for Clinical Instructors. Bellarmine University, Clinical Instructor Conference.

Reibel, M. (2007). Qualities of an Effective Clinical Instructor. Bellarmine University, Clinical Instructor Conference.

Reibel, M. (2005). Student Drawing; A Clinical Learning Tool. Bellarmine University, Nursing Education Conference.

Reibel, M. (1990). Nutritional Support in the Critically Ill Patient. Norton Hospital Audubon. Continuing Education Program.

RN Licensure

State of Kentucky, License 1054221, 1985-*present*.

Certifications

Cardiopulmonary Resuscitation (CPR)- Current
Advanced Cardiac Life Support (ACLS), 2002