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## Merging Educational Technology into Routine Care for Patients Living with Fibromyalgia

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MERGING EDUCATIONAL TECHNOLOGY INTO ROUTINE CARE  
FOR PATIENTS LIVING WITH FIBROMYALGIA

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**THE GRADUATE COLLEGE**

We recommend the doctoral project prepared under our supervision by

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## EXECUTIVE SUMMARY

Fibromyalgia is a complex and challenging disorder of unknown etiology; however the management of patients with fibromyalgia is becoming facilitated more often by Advance Practice Registered Nurses (APRN). Unfortunately, the lack of clarity in diagnosis, variances in practice guidelines, time constraints and the resources required for APRNs to adequately manage fibromyalgia can be extensive. The evidence supporting nonpharmacological strategies is strong; yet implementation of these strategies into routine care has not been sufficient.

Substantial research in the past five years has resulted in new diagnostic criteria intended to simplify the fibromyalgia diagnosis. Moreover, new clinical practice guidelines stress the importance of utilizing health technologies to educate patients about fibromyalgia beginning at diagnosis and continuing throughout management. Included in the new practice guidelines is FibroGuide, an interactive educational DVD-ROM shown to reduce symptom severity and enhance self-management for patients with fibromyalgia.

The following Capstone Project implemented FibroGuide into the routine care of 35 patients living with fibromyalgia. The FibroGuide project evaluated two outcomes of interest: patient perspectives of health education using health technology to assist in self-management, and overall effect on function after implementing FibroGuide. After 12 weeks of using FibroGuide, participants showed a significant improvement in function ( $p = .017$ ) and thought FibroGuide and health technology had potential toward enhancing self-management. Implementing FibroGuide into routine care of patients with fibromyalgia had clinical application in the context of providing evidence-based care that can improve overall function and facilitate self-management.

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## CHAPTER 1

### INTRODUCTION

Fibromyalgia (FM) is a chronic disorder of unknown etiology characterized by abnormal pain processing in the central nervous system (Arnold, Clauw, Dunegan, & Turk, 2012). Individuals living with FM suffer from recurrent physical, psychological, behavioral, and social impairments affecting everyday activities (Camerini, L., Camerini, & Schulz, 2013). The majority of patients isolate and withdraw from friends and family; they complain of debilitating widespread pain, excessive fatigue, muscle stiffness, nonrestorative sleep, inactivity, irritability, depression, anxiety, headaches, numbness and tingling, decreased libido, bladder and bowel insufficiencies, and severe problems with focus, concentration, and thought clarity (Arnold et al., 2012; Wells-Federman, 2000). Subsequently, although patients with FM appear fine externally; they suffer internally with agonizing physical pain and emotional sickness.

According to the Centers for Disease Control and Prevention (CDC) (2012), the prevalence of FM is seven times greater in women than men and affects 2%-5% of adults in this country. Most individuals are diagnosed with FM during middle age and the prevalence increases with age; though diagnosed less frequently, FM is seen in children and adolescents as well (Buskila & Ablin, 2012; CDC, 2012). In addition, 84% of patients with FM have one or more comorbidities that further complicate and delay diagnosis, including: musculoskeletal, psychological, gastrointestinal, cardiovascular, genitourinary, respiratory, and endocrinological disorders (Quwieoz, 2013). Moreover, direct and indirect health care costs were 2-3 times higher for patients with FM compared to costs for patients without FM (CDC, 2012). According to Kasper (2009),

FM patients had far more emergency department visits, clinician and physical therapy appointments, work or school absenteeism, reduction in productivity, and disability claims than those with other pain-related disorders.

In recent years, FM research has shown greater evidence for dysregulation of pain processing in the central nervous system. This finding resulted to changes in diagnosis and two new published guidelines (Arnold et al., 2012; Fitzcharles & Yunus, 2012). First, the American College of Rheumatology (ACR) expanded its 1990 diagnosis criteria and included symptoms beyond pain (Arnold et al., 2010). Following the ACR's changes in 2010, a faculty of 23 leading experts in FM management that included primary care practitioners and specialists from rheumatology, pain, neurology, and psychiatry formed the FibroCollaborative initiative and identified core principles and practical strategies for managing FM (Arnold et al., 2010). Following the FibroCollaborative initiative, two years later the Canadian Pain Society published another clinical guideline. Both guidelines showed similarities by emphasizing nonpharmacologic treatment approaches and psychoeducation taking place in primary care. In addition, the FibroCollaborative recommended that providers use health technology and an interactive computer-based program called FibroGuide to aid patients in building self-management skills that are necessary to manage FM (Arnold et al., 2010).

The FibroGuide program was originally developed and implemented by researchers from the Chronic Pain and Fatigue Research Center at the University of Michigan as part of a six-month randomized controlled study (Williams et al., 2010). Williams et al. (2010) and researchers created a health technology program that translated traditional face-to-face cognitive behavioral therapy into an educational self-management

website for patients with FM; study results showed patients in the FibroGuide group demonstrated significant improvements in symptom reduction and physical function, and showed greater progress in the management of fatigue, sleep, anxiety, and depression.

FibroGuide is comprised of 10 evidenced-based modules: understanding FM, communicating with family and health care providers; being active; improving sleep; relaxing; coping with fibro fog; setting goals; pacing self; thinking differently; and making time for self (Appendix A). Each module contained expert videos, readings, and worksheets that have theoretical grounding and empirical support from traditional face-to-face models and have been shown to help patients with FM gain better knowledge about the disease state, improve skills to help with symptom management, and adopt healthier lifestyle changes (Williams et al., 2012). Furthermore, FibroGuide was designed to help clinicians provide patients with more extensive knowledge about FM when time and resources were limited.

Research has shown that not only do FM patients have a greater personal preference for receiving health information through their computers, mobile devices, tablets, and the Internet, but that this also results to improved health outcomes (Camerini, L., Camerini, & Schulz, 2013; Daraz, MacDermid, Wilkins, Gibson, & Shaw, 2011; Hebda & Czar, 2013). In 2009, more than 80% of Americans owned a computer and accessed more than 70,000 health-related websites; and more than 60% of patients with FM reported confidence in the health information found online (Bailey, LaChapelle, LeFort, Gordon, & Hadjistavropoulos, 2013; Daraz et al., 2011; Korda & Itani, 2013; Younger, 2010). Advances in health technology make it possible for Advanced Practice Registered Nurses (APRN) to direct patients to FibroGuide by way of straightforward

access, privacy, and convenience of a patient-focused environment (Friedberg et al., 2012).

### **Problem Statement**

Fibromyalgia has become more of a clinical problem less seen in specialty clinics and more commonly managed by APRNs in primary care and other health care settings. The lack of clarity in diagnosis and variances in practice guidelines has left many APRNs uncertain of the best treatment modality. It is essential that APRNs be aware of the current diagnostic criteria as well as evidence-based strategies known to produce the greatest success in symptom reduction and self-management (Peterson, 2007). The evidence supporting nonpharmacological strategies for FM is strong; yet implementation of these strategies into routine care has been slow (Williams et al., 2010). Understanding the research behind the symptomatology and nonpharmacologic treatments will allow APRNs to deliver evidence-based care in primary care and other health care settings (Peterson, 2007).

According to Arnold et al. (2012) and Reed & Herrmann (2012), nonpharmacologic management of FM posed several challenges in the current health care system. First, clinicians reported difficulties communicating emerging information in that health care visits have not been sufficient to address all of the physical, psychological, and social needs of patients living with FM. Second, FM is a complex disorder compounded by physical, psychological, behavioral, and social impairments posing greater economic burdens on patients and health care resources. For example, patients with FM have 30% higher health care costs than non-fibromyalgia patients and are associated with up to 30 health care visits per year (Fitzcharles, 2012; White & Hearth,

2001). Third, engaging patients in self-management strategies is perplexing. After all, these strategies are often suggested only when other treatment attempts have failed to alleviate symptoms or improve function, leaving patients feeling more frustrated, hopeless, and unreceptive. Lastly, clinical practice guidelines remain controversial regarding how FM should be diagnosed and effectively treated. Eleven different practice guidelines have been published endorsing more than 20 combined nonpharmacologic and pharmacologic interventions (Reed & Herrmann, 2012; Timmermans & Mauck, 2005), leaving clinicians baffled over which recommendation is best. Most of the FM guideline methodologies have shown little promise for desired results nor demonstrated provider implementation; consequently, patients are not receiving evidence-based care (Timmermans & Mauck, 2005; Williams et al., 2010).

In developing a framework for managing FM in primary care settings, Arnold et al. (2012) recommended that clinicians stress the essential role that health technology and FibroGuide play in the initiation and ongoing treatment of FM. Above all, patient education is a fundamental element and must be an integral part of FM management. And yet, APRNs and other clinicians are not equipped to provide the more extensive information necessary to adequately educate patients in managing the physical, psychological, behavioral, and social impairments related to FM. Hence, there is a need for patients to stay well-informed about FM and to actively participate in their care.

At least six randomized controlled studies suggested that health technology was effective in reducing symptom severity, improving function, and enhancing self-management for patients living with FM (Arnold et al., 2012). FibroGuide was recommended as an educational approach and was available for this study in a DVD-

ROM (Arnold et al., 2012). Patients treated in this medical office setting with a diagnosis of FM were provided FibroGuide as part of their routine care. Evaluation was based on a patient-focused framework integrating self-management and nursing informatics resulting from the recommendation (Arnold et al., 2012) for FM; and provided quantitative and qualitative data for examining the usefulness of FibroGuide in self-management and functional outcomes.

## CHAPTER 2

### REVIEW OF THE LITERATURE

FM is a complex biopsychosocial condition where the difficulties in diagnosis and management make it impossible to have a single treatment strategy (Arnold et al., 2010). In the past, FM has been poorly understood, scrutinized with few resources, and managed with inconsistent treatment interventions due to variances among practice guidelines; this has contributed to the slow integration of nonpharmacological practice guidelines in patient care (Reed & Herrmann, 2011; Williams et al., 2010). However, recent research has suggested that nonpharmacological strategies that encourage health technology usage and self-management are, in fact, beneficial (Knight & Shea, 2013).

Evidenced-based treatment approaches for FM published by Arnold et al. (2010) showed substantial evidence that computer technology was an effective platform for the delivery of patient education and that, specifically, the FibroGuide program demonstrated improvements in physical, psychological, behavioral, and social impairments related to FM (Camerini, L. et al., 2013; Williams, 2010). Advances in health technology have made computer-based education attractive to clinicians and patients as part of routine care that addressed nonpharmacological, evidenced-based strategies that better met the individual needs of patients living with FM.

A systematic search of the electronic databases (PubMed, PsycINFO, CINAHL, and the Cochrane Library) between the years 2001 and 2013 was performed using the following MeSH terms: fibromyalgia, health technology, clinical practice guidelines, self-management, evidence-based care, quality websites, and patient education. In addition, the following journals were reviewed as part of the integrative review: *Current*



*Psychiatry, Journal of Pain*, and the online archives of the *British Medical Journal*. The following books were also used to collect data on FM: *Clinical management of fibromyalgia*, *Managing pain before it manages you*, and *Fibromyalgia: A practical clinical guide*. The inclusion criteria were studies published in peer-reviewed journals that included nonpharmacologic management strategies for FM, evidence-based information delivered from the Internet for FM, and current clinical guidelines for FM. The following websites were viewed for scientific evidence and up-to-date information: Expert Patients Programme, FibroGuide, painACTION-back pain, PatientsLikeMe, and X-Plain. Exclusion criteria included studies with a primary focus on pharmacologic treatment.

### **FM Burden**

Literature from 2001 to 2013 described the recurrent physical, psychological, behavioral, and social burdens reported by patients with FM (Camerini, L. et al., 2013). Most patients described physical symptoms beyond widespread pain that included severe fatigue, nonrestorative sleep, irritable bowel syndrome, bladder dysfunction, morning muscle stiffness, headaches, dizziness, extremity numbness, allodynia, hyperalgesia, paresthesia, and dysmenorrhea (Arnold, 2012; Fitzcharles & Yunus, 2012). In addition, patients reported psychological problems with mood and emotional regulation, as well as anxiety, post-traumatic stress, memory loss, and cognitive impairment termed “fibro fog” (Arnold, 2010; Fitzcharles & Yunus, 2012; Goldenberg, 2009; Marcus & Deodhar, 2011; Nihalani, Schwartz, & Chlebowski, 2006; Russell, 2006; Stahl & Briley, 2009; Uguz et al., 2010). The burden of these physical and psychological symptoms had considerable effects on patients’ level of activity, work attendance and productivity, daily task

completion, and connections to family and friends (Dennis, Larking, & Derbyshire, 2013; Goldenberg, 2012).

The onset of FM symptoms is generally subtle and worsens over time, but they may also appear suddenly following a physical or mental trauma (Fitzcharles & Yunus, 2012). According to Stahl, Briley, and Speath (2009), FM is fundamentally different from other pain or rheumatic disorders in that FM is not caused by tissue, muscle, or joint damage and inflammation.

Besides the burden to patients and their loved ones, studies showed that patients with FM had far more emergency department visits, physician visits, and physical therapy appointments compared to patients with other pain-related disorders (Kasper, 2009). Diagnosis can take up to five years, further delaying treatment and increasing costs to patients and health care systems (Kasper, 2009; Smith et al., 2011). Smith et al. (2011) reported that the annual direct patient costs for physician office visits, diagnostic tests, prescriptions, emergency department visits, and out-of-pocket expenses totaled \$7,973 for FM patients, compared to \$4,013 for patients without FM. Annual indirect costs related to absenteeism and disability, according to Smith et al. (2011), totaled an additional \$10,697.

### **Practice Guidelines**

To assist APRNs and other health care providers addressing the burdens of FM in making decisions based on clear evidence, several clinical practice guidelines have been published. The first clinical study on FM was completed in 1981 (Reed & Herrmann, 2012). Following this study, Dr. Philip Hench, a rheumatologist, published the first clinical guidelines in 1986, suggesting that physical, behavioral, psychological, and

pharmacological interventions would be the most effective treatment (Reed & Herrmann, 2012). In 1990, after examining more than 3,000 peer-reviewed studies, the ACR established two criteria for FM diagnosis: patients experiencing at least three months of unexplained widespread pain, and patients having a pain response to 11 or more of 18 tender pressure points located on the right and left sides of the body, above and below the waist, and on the axial skeleton (Goldenberg, 2012).

Two decades later, research showed stronger evidence that the pathophysiology of FM was located in the central afferent processing system (Arnold et al., 2012). In light of new evidence, the ACR updated and revised its old diagnostic criteria in order to simplify diagnosis for primary care providers (Arnold et al., 2012). The new criteria were updated in 2010, revised in 2011, and revised in 2012, recommending the use of the Widespread Pain Index (WPI) and Symptom Severity (SS) scale to measure symptoms, and adding to the criteria that no other disease can explain the patient's symptoms (Garg & Deodhar, 2012; Smith et al., 2011). Meanwhile, 23 leading faculty members and experts in FM formed the FibroCollaborative initiative in 2010 and developed an evidenced-based approach to treatment based on the new diagnostic criteria established by the ACR. The FibroCollaborative's members collectively reviewed medical literature and developed a state-of-the-art framework and guidelines for primary care providers to better understand, assess, diagnose, and manage FM in the primary care setting (Arnold et al., 2010). Two years later the Canadian Pain Society (CPS) published another practice guideline (Fitzcharles et al., 2012).

Recommendations from both the FibroCollaborative framework and the Canadian Pain Society guidelines provided an overall approach to FM care, differing from previous

guidelines that mostly addressed treatment options (Fitzcharles et al., 2012). The Canadian guidelines recommended that FM diagnosis and management take place in primary care settings where patients typically received more comprehensive education and self-management skills through nonpharmacologic interventions (Fitzcharles et al., 2012). In particular, the primary care guidelines and education framework recommended FibroGuide to provide patients an evidence-based self-management program that can be effectively integrated into routine care (Arnold et al., 2010; Williams et al., 2010). Ultimately, successful FM self-management focuses on patients' confidence to carry out medical and emotional behaviors necessary to reach desired goals in a rich environment where knowledge and communication are derived from health technologies (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Knight & Shea, 2013).

### **Health Technology**

In a six-month randomized controlled study, Williams et al. (2010) found that FibroGuide showed significant symptom reduction and improved physical function. Patients assigned to the FibroGuide group reported pain reduction of 29% compared to standard care (8%),  $p < .008$ , and improved physical function of 31% compared to 6% with standard care,  $p < .002$  (Williams et al., 2010). Secondary outcomes for sleep, fatigue, anxiety, and mood did not show a statistically significant difference but resulted in some improvement over standard care (Williams et al., 2010). Furthermore, global impression of improvement was significantly higher than in the standard care group (Williams et al., 2010).

Randomized controlled studies in health technology and self-management for FM have shown positive impacts on function and quality of life (Ramos-Remus, Salcedo-

Rocha, Prieto-Parra, & Galvan-Villegas, 2000). Several studies found significantly lower pain severity, higher physical function, improved global function, and a greater number of days feeling better for patients who participated in psychoeducation groups focused on self-awareness, self-help, exercise, and cognitive behavioral therapy (Garcia et al., 2006; Hsu et al., 2009; Luciano et al., 2013; Rooks et al., 2007). Research showed that health technology and computer delivery platforms were an effective means to receive education, transfer knowledge, and develop self-management skills for FM patients (Camerini, L. et al., 2013; Hebda & Czar, 2013). Patients using these health technology programs reported satisfaction with the FM information and instruction they received (Claugh & Casey, 2011; Korda & Itani, 2013; Palyo & Schopmeyer, 2012; Stinson et al., 2013).

Furthermore, insomnia and anxiety, frequent symptoms of FM, have shown improvement in controlled studies using instructional computer-based programs (Carlbring et al., 2005; Ritterband et al., 2009). In other related back-pain conditions, two websites, painACTION-back pain and Patient Line, demonstrated improved outcomes for reducing pain, depression, anxiety, and stress, and improving adherence, knowledge, and self-management (Chiauzzi et al., 2010; Pellise & Sell, 2009).

Adequate time for patient education is often in short supply in busy health care settings, making it essential for APRNs to make optimal use of existing resources and practice guidelines (Arnold et al., 2010). Nonetheless, the management of FM can be optimized by implementing FibroGuide as recommended (Arnold et al., 2010) while sustaining a self-management and nursing informatics framework. FibroGuide is not a

substitute for face-to-face time with clinicians, but rather a collaborative way to deliver more extensive health information necessary to manage FM (Bartleson, 2006).

## CHAPTER 3

### THEORETICAL UNDERPINNINGS OF THE PROJECT

#### **Theory to Support Change**

Change plays a significant role in health care practices regardless of practice size, specialty, or age. Kurt Lewin developed his change method theory in the 1940s; his ideas of motivation and change in the workplace remain relevant in the 21st century. Lewin's theory works well because the change process he envisioned involves action planning, fact gathering, and communication throughout each of his three stages of change, known as unfreeze, movement, and refreeze (Lee, 2005). This process ensures clearer expectations and shared understandings for those involved in and affected by the desired change (Lee, 2005).

In Lewin's theory, unfreezing disrupts the current system or processes and sets in motion the anticipated or desired change (Lee, 2005). The second stage, movement, encourages people to adopt the change by promoting open communication and active involvement. The third stage, refreeze, reinforces new patterns of behaviors to sustain the change by providing ongoing assistance and support to individuals using the new system (Lee, 2005).

In the first stage of change for this project, the DNP student engaged patients in open discussions during routine medical appointments that gathered information about where patients obtained knowledge regarding their FM and whether the information was beneficial or misleading. Unfreezing the current practices for seeking health information was used to design and create strategies to transition patients from traditional education practices to health technology practices that offered unprecedented performance,

adaptability, and cost effectiveness. During the unfreezing stage, staff and patients were motivated to accept the upcoming change. Movement through the implementation phase provoked some patient resistance (e.g., some reported difficulties using the DVD-ROM; several had trouble finding time to use FibroGuide; and others were disinterested in the program). However, many patients accepted FibroGuide and began to actualize this way of self-management as a benefit to their care. Refreezing or sustaining FibroGuide as a health technology approach to self-management required time for patients to master the new technology and develop strategies that incorporated FibroGuide into their daily routine. The APRN remained available to ensure that emerging information was translated to patients either through telecommunication or face-to-face interaction. As with any treatment strategy, not every patient with FM benefited from FibroGuide and some patients required more individualized care.

### **Theory to Support Framework for Self-Management and Nursing Informatics**

The FibroGuide as a health technology project for FM used the Empowerment Informatics (EI) framework developed by Knight and Shea (2013) (Appendix B). Under the EI framework, patients living with FM and APRNs collaborate to use health technologies to support self-management behavior within the context of each patient's characteristics and individual goals (Knight & Shea, 2013). Self-management is derived from the patient's values and needs as part of a concordance approach, rather than compliance approaches (Knight & Shea, 2013). With the concordance approach, patients learn how to live with FM and are empowered and motivated by emerging knowledge, practical skill, and personal experience that focus on their own concept of health (Schermer, 2009). In turn nursing informatics integrates data, information, and



knowledge in the decision-making process through information structures, methods, and technology (Knight & Shea, 2013). Furthermore, self-management behaviors still affect empirical indicators of patients' health and resources; however, these effects are secondary to quantitative improvements in patients overall function (Knight & Shea, 2013).

Self-management, technology, nursing, and informatics theories are integrated within the EI framework. These theories include: Bandura's self-efficacy; nursing's metaparadigm (person, environment, health, and nursing); technology's field of human factors and sociotechnical theory; and the informatics research organizing model (Knight & Shea, 2013). These theoretical underpinnings aid in the approach to self-management and health technology for patients and clinicians.

Under the EI framework, the DNP student used FibroGuide as a health technology approach to enhance routine care of patients living with FM. Utilizing the EI framework allowed for evaluation of two outcomes of interest: patient perspectives and functional outcomes with FibroGuide. Patients' perspectives of self-management were evaluated through data provided from the activity logs, FibroGuide module selections plus their responses to six open-ended questions, while the Fibromyalgia Impact Questionnaire Revised (FIQR) (Appendix F) provided quantitative data on the effectiveness of FibroGuide in improving patient function. Both outcomes of interest are of importance to APRNs working in primary care and other health care settings using health technology to assist in providing nonpharmacologic interventions to patients living with FM. The EI framework integrates theory and evidence surrounding self-

management and nursing informatics that support APRNs' approaches in the management of FM.

## CHAPTER 4

### METHODOLOGY

#### Needs Assessment

Despite the ACR's simplified diagnostic criteria and the FibroCollaborative practice guidelines, many APRNs and other clinicians remain uncertain about the diagnosis and management of FM. Practice guidelines recommended that FM management take place in primary care settings and placed considerable emphasis on patient education and self-management (Arnold et al., 2012). However, clinicians are faced with limited time and few available resources that provide all of the information necessary for patients to self-manage FM.

For the purpose of this study, a needs assessment was derived from four sources:

1. An extensive review of the literature from 2001 to 2013 supported the consensus that FM is a complex, chronic disorder with inconsistent guidelines posing significant management challenges to APRNs;
2. The management of FM is no longer exclusive to specialists and there is greater need for understanding diagnosis and management in primary care settings;
3. The study site and DNP student experienced a 50% increase in FM patient referrals between 2010 and 2011; and
4. A hospital community needs assessment completed in 2013 showed a need for greater chronic disease management.

In the latter source, St. Luke's Boise Medical Center conducted a community needs assessment (2013) looking at arthritis, which is similar to FM in symptoms and comorbidities. The results showed that in 2009, 23.7% of Idaho adults had been told by a

medical professional that they had arthritis. A majority of those with arthritis (54.5%) reported that their activities were limited because of health problems. The need for chronic disease management ranked high in the assessment because the number of people with chronic conditions is trending higher and this is a contributing factor to a number of other health concerns. For Idaho, 15.4% adults reported their health status as fair or poor, up from 13.4% in 2002, which is now above the national average. Furthermore, according to the St. Luke's assessment, Idahoans reported poor physical health an average of 2.6 days per month and poor mental health 2.3 days per month.

### **Population Identification**

The U.S. Census Bureau (2013) reported Idaho's population was 1,612,136 with the population of Ada County at 409,061. Boise is the largest city in Ada County and is the primary hub for health care for a population of 212,303. Additionally, Ada County was designated a primary care health professional shortage area, with 94.5 active physicians per 100,000 residents (U.S. Census Bureau, 2013). Adding to this shortage, neighboring Canyon County, with a population of 193,888 (U.S. Census Bureau, 2013), lies within a 15-mile radius of Boise and reported only 35.5 active physicians per 100,000 residents, indicating that many from this area also seek health care in Boise. According to the Idaho behavioral risk factor surveillance system (2012), 19.3% of Idahoans were without health care insurance, which impacted their ability to access health care services of any type. This is of significant concern because FM management has shifted from the specialist to primary care and research showed that health professional shortage areas are associated with poorer health outcomes due to decreased access to care (Guagliardo, 2004).

## **Identification of Project Sponsor and Key Stakeholders**

The DNP student as the primary APRN served as the project sponsor and key stakeholder in a solo practice. Subsequently, other interdisciplinary health care providers such as therapists, counselors, primary care providers, and specialists as well as patients' families, friends, or employers shared vested interests in patient outcomes.

## **Cost-Benefit Analysis**

Understandably, research has demonstrated a clear need for better management in the care of patients living with FM. Studies of FM showed the burden of illness and costs to patients and society were higher compared to other chronic illnesses such as rheumatoid arthritis, osteoarthritis, diabetes, and hypertension (Annemans, LeLay, & Taieb, 2009). Direct and indirect health expenses were twice as much for FM patients compared to individuals without FM (Smith et al., 2011). Extensive office visits for diagnosis, treatment, and management also created an economic burden for clinicians and their practices (Brown et al., 2011). Patients with FM had four times as many office visits than controls over a 12-month period (Brown et al., 2011). Subsequently, by the time an individual with FM was finally diagnosed with treatment initiated, they had been seen 25 times in the office and had received at least 11 prescriptions, compared to controls with 12 visits and 4 prescriptions (Brown et al., 2011).

Early diagnosis and initiation of FibroGuide as recommended (Arnold et al., 2012) were expected to optimize the management process, thereby decreasing unnecessary patient utilization of health care services and decreasing excessive APRN time spent with patients. FibroGuide was expected to assist patients in gaining self-

management skills, decreasing symptom severity, and optimizing function, thereby reducing absenteeism at work or school.

### **Scope of the Project**

This project implemented FibroGuide into the routine care of patients living with FM. Guidelines emphasized the importance of initial and ongoing education and health technologies which have been shown to reduce the severity of symptoms and increase the level of function by improving self-management in patients with FM.

### **Project Tasks and Personnel**

The first phase of this project examined practice guidelines for FM including the ACR's new and revised diagnostic criteria as well as recommendations for primary care management of FM published by the FibroCollaborative initiative (Arnold et al., 2012). After review, FibroGuide was selected for the project study because of its evidence-based content supported by a six-month randomized controlled study (Williams et al., 2010).

The second phase of this project identified 53 adult patients diagnosed with FM actively receiving pharmacologic and nonpharmacologic treatments for comorbidities or other mental health issues in the project setting. About 60% of the patients were referrals from other health care providers and the other 40% of the patients had primarily carried a psychiatric diagnosis where FM developed or was discovered during the course of treatment.

The third phase followed approval from the Institutional Review Board (IRB) on November 18, 2013, to evaluate FibroGuide in the routine care of patients living with FM. Two administrative staff were trained and instructed about the structure, timeline, purpose, objectives, and processes in this project. A two-hour meeting allowed staff to

become familiar with the FibroGuide DVD-ROM contents and to troubleshoot any problems. Following staff training, the 53 identified patients were immediately notified by mail, phone, or face-to-face conversation of the project and details for study participation.

In the fourth phase of the project, the FibroGuide DVD-ROM was distributed to 44 voluntary participants who agreed to participate and use the FibroGuide DVD-ROM. Participants were shown the office website (Appendix C) where they could sign and submit their informed consent (Appendix D); demographic survey (Appendix E); Fibromyalgia Impact Questionnaire Revised (FIQR; Appendix F); FibroGuide DVD-ROM; weekly activity log (Appendix G); six open-ended question survey (Appendix H); and an office contact in the event of problems. Participants were asked to spend at least 15 minutes per week using FibroGuide and in addition received weekly participation reminders via emails or phone calls. Data were deidentified so that no data could be linked to participants and all forms were submitted online through the project setting website.

The fifth phase concluded the 12-week project. Participants were notified and asked to complete the FIQR again, submit their activity tracking log, and answer six open-ended questions about their experience with FibroGuide and the computer's usefulness.

The final phase reviewed the data and results for FibroGuide and the assistance it provided participants in the routine care of FM management. This evaluation focused on two areas: patient perspectives of the health education and self-management and overall function after implementing FibroGuide.

## **Mission, Goals, and Objective Statements**

This project aimed to implement current diagnostic criteria and practice guidelines published by the FibroCollaborative initiative for primary care providers. FibroGuide was selected as an evidence-based health technology program consistent with progress made in research that supports the ACR's 2010 and 2011 recommendations for diagnosis and as a framework based on the recommendations for primary care in managing FM (Arnold et al., 2012).

## **Setting**

FibroGuide was implemented into the routine care of 35 out of 44 consenting FM patients who agreed to participate. Nine participants did not sign the informed consent or follow through with the FibroGuide project. The project setting is an outpatient health care practice owned by the DNP student and located in Boise, ID. The DNP student is a licensed APRN who provides pharmacological and nonpharmacological treatments to children, adolescents, and adults. In addition to the APRN, there were three licensed professional counselors, two administrative staff, and an off-site collaborating psychiatrist. The site's comfortable, well-maintained offices, waiting room, and receptionist area provided privacy and safety for nearly 1,000 patients seeking primarily mental health care with private or public payment options. For the purpose of this project, a separate office and computer were available for participants who did not have a home computer to use FibroGuide.

## **Population of Interest**

Fifty-three adult patients treated by the DNP student in the setting had a provisional or confirmed diagnosis of FM and were invited to use the FibroGuide DVD-



ROM as part of their routine care. The provisional diagnosis was given when a patient reported or presented to the DNP student with symptoms of widespread pain, mood disturbance, emotional dysregulation, fatigue, nonrestorative sleep, morning stiffness, irritable bowel syndrome, or cognitive impairment that was not otherwise attributed to another disorder (Arnold et al., 2012). A provisional diagnosis of FM was attained pending a full neuro-musculoskeletal physical exam by a primary care provider or specialist to rule out other possible causes.

### **Measures, Instruments, and Activities**

Each participant completed a demographic survey, pre-post FIQR, an activity log, and six open-ended questions. The demographic survey identified age, gender, occupation, education, race/ethnicity, the duration of treatment, computer access, and Internet usage. The FIQR is a common instrument used in FM management; it measured pre-post patient symptom severity, impact, and function. The FIQR was updated in 2009 to improve deficiencies in wording, omissions, concepts, and scoring noted in the original FIQ, which has been used in over 500 studies (Bennett et al., 2009). The updated FIQR has acceptable psychometric properties that discriminate between FM and rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), and Major Depression Disorder (MDD); it can be completed in two minutes and scored in less than one minute (Bennett et al., 2009). Permission and copyrights are noted in Appendix I.

In addition, participants completed the activity log and tracked FibroGuide modules most viewed and time spent, as well as answered six open-ended questions that provided qualitative data on their perspective on FibroGuide and the computer platform to assist in self-management.

## **Timeline**

January 2013-June 2013

- Committee chair and member selection
- Proposed capstone project
- Revised and defended proposal

July 2013-February 2014

- Updated literature review: most current evidence, data collection
- Submitted original application to IRB (July 2013)
- IRB approval (August 22, 2013)
- Submitted modification application to IRB (November 2013)
- IRB approval (November 23, 2013)
- Data collection (November 23, 2013-February 15, 2014)

February 2014-March 2014

- Conducted data analysis, interpretation, application to practice
- Completed capstone final paper

April 2014

- Defend capstone project
- Submit final paper to UNLV Graduate College

The detailed timeline is available in Appendix J.

## **Effects on Health Care System and Practice**

New simplified diagnostic criteria, updated primary care guidelines, and evolving health technologies have changed the way patients and APRNs gather and use health information in the diagnosis and nonpharmacologic management of FM. Notable

improvements have been documented in the literature showing reductions in symptom severity and improvements in physical function leading to better perceived self-management. The implementation of the FibroGuide DVD-ROM as a health technology had application in the context of APRN patient-focused care where clinical practice has been slow to implement evidence-based nonpharmacologic strategies for FM (Williams et al., 2010).

Furthermore, the management of FM is labor intensive, time consuming, and costly, and places high burdens on patients and health care providers (Stahl, 2009). In the current fee-for-service system, clinicians have to work more efficiently to sustain economic health and at the same time achieve success in the management of FM patients. With a better understanding of diagnosis and treatment, APRNs can offer patients evidence-based strategies to relieve the burden and suffering. Health technology programs are a practical approach for managing FM and offer several advantages, including convenience, privacy, control of information flow, self-pacing, and improved patient-provider decision-making (Pellise & Sell, 2009). In most cases, patient participation and self-management will result in fewer health care visits and decreased health care costs (Ritterband et al., 2009).

### **Resources and Supports**

The FibroGuide DVD-ROM served as the health technology resource for participants of the project. Two trained administrative office staff provided assistance for participant contact, recruitment, data organization, weekly reminder calls and emails, and troubleshooting questions for participants challenged by operating the FibroGuide DVD-ROM. The DNP student continued the role as the APRN and provided the usual and

customary pharmacologic and nonpharmacologic mental health care in addition to adopting FibroGuide into routine care. Established collaboration with the off-site psychiatrist remained during the project. On-site Licensed Professional Counselors were available to participants in the event that additional counseling services were needed. CompNet Systems maintained the computers, software, and technical support. IBiz Inc. developed the confidential and secure link on the APRN practice's website to access the participation consent, surveys, activity log, and open-ended questions. Throughout the project, a quiet private office equipped with a computer and Internet access was available during business hours for participants who have no access to a computer.

### **Risks and Threats**

Minimal threats were associated with aspects of the project. Three participants required additional staff assistance to locate FibroGuide from the DVD-ROM after inserting it in their computer. There were no reports of failure from the FibroGuide program, personal computer, or lack of voluntary participants. No sensitive personal or psychological data were collected or reported.

Risks to participants were minimal and were no different from typical office visits. No identified reports or evidence of negative changes in mood, behaviors, fatigue, anxiety, pain, or cognitive function were seen as the result of participation in the study. Participants were informed that if at any time they experienced adverse events or became uncomfortable using FibroGuide, a complete withdrawal from the project was acceptable and would not affect their established care.

## **Evaluation Plan**

The aim of this project was to evaluate the impact of FibroGuide on participants' perspective of health education and health technology in achieving self-management and overall function. Each participant completed the FIQR before and after implementing FibroGuide that measured functional outcomes related to symptom severity, impact of FM, and physical function. In order to evaluate participant perspectives of FibroGuide, each participant completed an activity log that identified time spent and which FibroGuide modules were most used during the 12 weeks. In addition, each participant answered six open-ended questions: what they thought of FibroGuide; how FibroGuide assisted in their self-management; barriers or challenges; if the patient planned to continue using FibroGuide; feelings about computer use to receive patient education; and preference for method of obtaining health information. Participants ranked on a scale of 1-5, 1 being high and 5 being low, their preference for obtaining their health information: Internet/websites; DVD/videos; brochures/books; conversation with clinician; or TV/news media.

## **Marketing Plan**

Julie Bernardini, the creative director of FibroGuide, and Susan Collins, the public relations director with Health Education and Research Development, distributed the FibroGuide DVD-ROM to the DNP student with permission to copy and use it in this project (Appendix K). Immediately following IRB approval, the 53 patients identified with a provisional or confirmed diagnosis of FM were notified face-to-face, by mail, or by telephone of this project. Interested volunteers were given a free copy of the FibroGuide DVD-ROM along with verbal and written instructions. The office website

provided easy access for the consent form, surveys, and activity log. Furthermore, announcements were posted in the counseling offices, waiting room, and the DNP student's office advising patients of this project. No one was denied access to FibroGuide and those not wanting to participate in the project did not receive the FibroGuide DVD-ROM but could request copied information from the modules.

### **Financial Plan**

Costs for this project were relatively low. The FibroGuide DVD-ROM was provided to the DNP student at no cost. Fifty FibroGuide DVDs and three USB flash drives were copied by the DNP student and office staff using the office computer at a total cost of \$75.00. Staff time for training and participation in the project was difficult to estimate because project activities were completed during down time and in between patient appointments over the course of a regular day. Neither staff nor the DNP student needed additional time outside of the work day to complete this project. Costs for paper, postage, and envelopes for mail notifications and DVD-ROM mailings totaled \$68.00. There were no additional costs associated with computer problems, software, or office space. The office website and links to the study materials did not present any additional costs. Overall cost for this project was \$143.00 (Appendix L).

### **Institutional Review Board Approval**

The University of Nevada Las Vegas Institutional Review Board (IRB) granted approval for the implementation of FibroGuide into the routine care of patients living with FM on August 18, 2013 (Appendix M). However, a modification to the study was submitted after the FibroGuide website was removed from public access. A request to use

the FibroGuide DVD instead was granted by the IRB on November 23, 2013 (Appendix N).

## CHAPTER 5

### SUMMARY OF IMPLEMENTATION AND RESULTS

#### **Initiation of the Project**

Patient education plays a significant role in successfully managing FM and must be integrated with the diagnosis and continue throughout management. Education initiates a course for patients to empower themselves with knowledge and skills needed to self-manage and gain control over FM (Arnold et al., 2010). FM education can occur individually between clinician and patient, in support groups, and through books, brochures, media, the Internet, and more popular health technology programs (Paiva & Jones, 2012). Regardless of the medium, it is important that health information be derived from current evidence.

In an effort to better understand the pathophysiology and diagnosis of FM, the ACR carefully constructed simpler diagnostic criteria with the hope that APRNs, primary care providers, and other clinicians could diagnose and manage FM with more confidence. As a result of the ACR's changes in diagnostic criteria, recommendations for management of FM in primary care and the Canadian Pain Society guidelines for FM were published. Both guidelines similarly emphasized that patient education was the fundamental approach for managing FM. In particular, Arnold et al. (2012) recommended that clinicians direct patients to FibroGuide to gain the more extensive knowledge and understanding necessary for self-management of FM.

As a solo practice APRN, the DNP student recognized the need to improve FM management based on the simplified and expanded diagnostic criteria published by the ACR and recommendations published by the FibroCollaborative initiative. Fifty-three



patients in the clinic were known to have a diagnosis of FM. In a solo practice, this is a fair number of patients with FM to manage independently. Forty-four of these patients volunteered to implement FibroGuide as part of their routine care for FM and 35 participants completed the 12-week project. Under shared leadership, the DNP student and staff collectively shared responsibilities for training, recruitment, initiation of FibroGuide, reminder calls and emails, data collection, troubleshooting, and process evaluation. Patients were accustomed to the team approach to their usual care in the practice setting. Further, it was not practical for one person alone to complete this project; rather, staff participated collectively in the project activities, although the DNP student took primary overall responsibility for the practice change.

### **Threats and Barriers**

Although the project was deemed successful, predictable and unforeseen challenges occurred. Most significantly, the FibroGuide launch was originally set for implementation on September 1, 2013; however, the FibroGuide public website was removed from online access on August 30, 2013, thus creating delays and difficulties for participants who were eager to get started. Fortunately, FibroGuide was available in a DVD-ROM format. Only one copy was available, however, so additional copies had to be made by the DNP student. Because the FibroGuide format of delivery changed from online to DVD-ROM, modification from the IRB was requested, further delaying project implementation. Hence, there was a total delay of 12 weeks, which resulted in several concerns: Patients lost interest in the project and needed to be re-encouraged; copying DVD-ROMs increased costs; the copied DVD-ROMs created some minor problems for a few participants; USB flash-drive copies had to be made for patients without a CD-ROM

drive on their computers; and working with DVD-ROMs was slightly more cumbersome for participants than simply accessing a website.

Among other challenges and limitations, the DNP student, as the APRN provider in the project setting, was limited in her ability to engage and motivate patients in order to minimize bias. Also, the study time was limited to 12 weeks. Furthermore, although 44 patients agreed to participate, only 35 patients completed the study. Finally, the study relied on a single instrument (the FIQR) to measure clinical effectiveness, which did not allow determination of the effect of the intervention on other health outcomes related to FM.

Under the EI framework, the DNP student as the APRN provider was able to implement the project design and evaluate the use of health technology as part of self-management. The EI framework guided a patient-focused approach using FibroGuide to empower participants to use technology strategies in the management of their FM. Lewin's change theory brought about a strategic plan that motivated and prepared participants for the change in the delivery of information; encouraged participants to adopt FibroGuide; and reinforced FibroGuide as a fundamental component of their routine care for FM.

### **Monitoring**

All participants were provided a FibroGuide DVD-ROM or USB flash drive with verbal and written instructions. One week following the FibroGuide distribution, each participant received a phone call or email to ensure that there were no problems with the DVD-ROM or USB flash drive or FibroGuide program and that they were able to access content. Each participant completed and submitted online the participation consent,

demographic survey, and the first FIQR. These were sent to a secure email that only the DNP student could access to verify completion. Participants received weekly reminder phone calls or emails throughout the 12-week study. One week prior to study completion, participants were notified and asked to complete and submit the second FIQR and the activity log, as well as answer the six open-ended questions. Completed surveys were confirmed by the secure email.

### **Data Collection**

The study website served as the data collection site. IBiz Inc. created a link and added the informed consent, demographic study, FIQR, activity log, and six open-ended questions online specifically for this study. Participants anonymously completed and submitted the forms and surveys, with results being emailed to a secure address available only to the DNP student. At the conclusion of the study, the DNP student recorded the data in Excel for analysis.

### **Data Analysis**

Demographic variables as shown in Table 1 included: age, marital status, gender, education, employment, race/ethnicity, computer ownership, Internet access and use, and length of treatment for FM in years. The participant sample was  $n=35$  and mean age was 51 years old ( $SD=13.4$ ), with 31.4% of participants married and 68.6% unmarried (which included single, divorced, widowed, or having a significant other). Females made up 91.4% of the sample. Participants were 88.6% Caucasian and 11.4% Hispanic. The mean number of years since being diagnosed with FM was 9.51 years ( $SD=7.3$ ). In terms of education level, 8.6% of participants did not graduate from high school, 42.9% had some college, and 48.6% had 14 years or more of education, while 48.6% reported being

employed and 51.5% reported being unemployed or disabled. In technology use, 91.1% of participants owned a computer and 94.3% had Internet access; participants spent an average of 2.26 days per month looking for FM information online.

Table 1

*Descriptive Statistics of the Sample*

Variable	N (%)	Mean	Median	Mode	SD
Age (21-79)	35 (100%)	51.09	52.00	39	13.441
Marital status	35 (100%)				
Single	9 (22.9%)				
Married	11 (31.4%)				
Divorced	12 (34.3%)				
Widowed	2 (5.7%)				
SO	2 (5.7%)				
Gender	35 (100%)				
Male	3 (8.6%)				
Female	32 (91.4%)				
Education (years)	35 (100%)				
<12	3 (8.6%)				
12-14	29 (82.8%)				
16-18	3 (8.6%)				
Employment	35 (100%)				
Employed	17 (48.5%)				
Unemployed	9 (25.8%)				
Disabled	9 (25.7%)				
Race/Ethnicity	35 (100%)				
Caucasian	31 (88.6%)				
Hispanic	4 (11.4%)				
Own computer	35 (100%)				
Yes	34 (97.1%)				
No	1 (2.9%)				
Internet access	35 (100%)				
Yes	33 (94.3%)				
No	2 (5.7%)				
Years of FM (1-25)	35 (100%)	9.51	6.00	5	7.346
Mo. Internet use	35 (100%)	2.26	1.00	0	5.918

The FIQR is a 21-question tool used in this project to measure the impact of FM on participating patients (Bennett, Friend, Jones, Ward, Han, & Ross, 2009). The FIQR is divided into three domains: activity level, overall impact, and intensity of symptoms. The sum scores of each domain were gathered for a total adjusted score from 0-100. The FIQR-1 total adjusted score before starting FibroGuide had a mean score 51.33 (SD=14.445) and the FIQR-2 total adjusted score after FibroGuide had a mean score 48.07 (SD=13.652) as shown in Table 2. The reduction in the total FIQR score from pre-FibroGuide to post FibroGuide suggested that participants experienced a decrease in FM severity and impact after implementing FibroGuide. Most studies showed that individuals with FM usually have a FIQR total score in the 40s and 50s, and for those with aggressive symptoms the total adjusted score will be much higher (Bennett et al., 2009).

Table 2

*FIQR Results*

Variable	N (100%)	Mean	Medium	Mode	SD
FIQR-1	33 (94.3%)	51.33	46.00	41	14.445
FIQR-2	28 (80%)	48.07	46.00	29	13.652

The project aimed to answer two questions:

1. From the participant perspective of health education and health technology did FibroGuide assist the participant in their self-management; and
2. After implementing FibroGuide, was there change in overall function?

A biostatistician assisted the DNP student in analyzing the data for this project.

The FIQR data were first tested for normality using the Shapiro-Wilk Statistic. FIQR at

time 1 (before FibroGuide implementation) met the normality criteria ( $W = .944, p = .141$ ), but FIQR at time 2 (after FibroGuide implementation) did not ( $W = .915, p = .026$ ). Therefore, a nonparametric test, the Wilcoxon Signed-Rank Test, was used to compare the paired FIQR scores. FIQR scores at time 2 ( $\bar{\chi} = 48.1, SD = 13.65$ ) were significantly lower than FIQR scores at time 1 ( $\bar{\chi} = 51.0, SD = 14.25$ ) using an exact, one-tailed test of significance ( $z = -2.107, p = .017$ ) suggesting that FibroGuide may assist participants in reducing the severity of symptoms and impact, and improve overall function.

Additionally, it should be noted that neither age nor years in treatment were significantly correlated with scores on the FIQR for either time period (all  $p$ -values  $> .10$ ); hence, the comparison of the FIQR scores did not need to be adjusted for these variables. This means that regardless of age and years of treatment for FM, the overall impact of FM does not appear to worsen over time and in fact can show improvement.

To address the patient perspectives on health technology and FibroGuide in assisting in self-management, 23 of the 35 participants (65.7%) answered the six open-ended questions. Results showed that 40% (valid 60.9%) of the participants wrote positive comments such as “I liked it”, “It was very useful”, and “It helped me.” In turn 17.1% of the participants (valid 26.1%) wrote comments indicating dislike or disapproval for FibroGuide, and 8.6% (valid 13%) wrote comments of uncertainty as shown in Table 3.

Table 3

*Open-Ended Questions*

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Liked	14	40.0	60.9	60.9
Did not like	6	17.1	26.1	87.0
Unsure	3	8.6	13.0	100.0
Total	23	65.7	100.0	
Missing	12	34.3		
Total	35	100.0		

When asked about how FibroGuide assisted the participants in their self-management, 31.4% reported that they were applying the new information and felt more controlled in the self-management of FM, 8.6% reported that they did not learn new information to assist in the self-management of their FM, and 25.7% were unsure if the information was going to better assist them in managing FM as shown in Table 4.

Table 4

*Open-Ended Assistance Question*

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
No	3	8.6	13.0	13.0
Yes	11	31.4	47.8	60.9
Unsure	9	25.7	39.1	100.0
Total	23	65.7	100.0	
Missing	12	34.3		
Total	35	100.0		

Participants reported barriers in the project such as: trouble finding time to use FibroGuide (25.7%), difficulty with the DVD-ROM or computer (17.1%), lack of interest



in FibroGuide (2.9%), and no barriers (20%). Some participants (17.1%) anticipated continuing to use FibroGuide, while 25.7% reported that they were not planning to use FibroGuide and 22.9% were unsure. The majority of participants reported that the computer was an effective and efficient way to receive education (42.9%), while 11.4 % reported that the computer was not useful and 11.4% were unsure. In addition, participants ranked from 1-5; 1 being the first choice, the preferred means for receiving health education: 37.1% preferred talking with their provider, 20% preferred the Internet/websites, 8.6% preferred brochures or books, 2.9% preferred the media, and no one preferred a DVD/Video as first line to receive health information. Although there is a limited range in statistical analysis, each item is guaranteed value and provided meaningful data from the participants' perspective.

Finally, participants were instructed to log the time they spent using FibroGuide and which FibroGuide modules they used during the 12-week study. Only 10% of participants recorded the amount of time they spent using FibroGuide, but for those who did record time, the minimum 15 minutes was noted. However, participants did record which FibroGuide modules they used. The two modules used most were "communicating" and "thinking differently," with 12.8% each, followed by "understanding FM," with 11.5%. "Sleep" and "pacing yourself" tied for third as shown in Table 5. This data demonstrated that most participants showed more interest in function than symptoms.

Table 5

*FibroGuide Modules*

	<i>N</i>	Percent	Percent of cases
Module 1: understanding FM	9	11.5 %	42.9%
Module 2: sleep	8	10.3%	38.1%
Module 3: setting goals	6	7.7%	28.6%
Module 4: communicating	10	12.8%	47.6%
Module 5: relaxing	7	9.0%	33.3%
Module 6: pacing self	10	12.8%	47.6%
Module 7: time for self	7	9.0%	33.3%
Module 8: being active	7	9.0%	33.3%
Module 9: fibro fog	6	7.7%	28.6%
Module 10: thinking differently	8	10.3%	38.1%
Total	78	100.0%	371.4%

**Giving Meaning to the Data**

**Quantitative Data**

Descriptive statistics were used to describe sample characteristics and frequencies of the participants and how this matched up to the epidemiology of FM reported in the literature. By comparison, Worldwide epidemiology suggested that FM is more prevalent in women, in patients over 50 years of age, in those with lower education levels and lower socioeconomic status (Queiroz, 2013). While participants in this study were predominantly female (91.4%) with an average age of 51 years, they were, contrary to the worldwide epidemiology, not of lower education (91.5% high school graduate plus college) or lower socioeconomic status (48.6% employed).

Statistical evaluation of patient function was determined by the Wilcoxon Sign-Rank Test, a nonparametric alternative to *t*-test, which is based solely on the order in which the observations from the samples fell. Due to the relatively small sample size, using the *t*-test may result in bias. Therefore, the Wilcoxon Sign- Rank Test was used to

test the change that occurred between pre-FibroGuide implementation and post-FibroGuide implementation. A significant difference ( $p = .017$ ) between pre-FIQR and post-FIQR mean scores was shown. This indicated that over a 12-week period, participants who used FibroGuide as part of their routine care for FM reported a reduction in symptom severity and impact as well as improved activity and function. These findings are consistent with previous studies evaluating patient education and nonpharmacological approaches to manage FM (Arnold et al., 2012; Camerini, L. et al., 2005; Chiauzzi et al., 2010; Fitzcharles et al., 2012; Williams, et al., 2010).

Secondary ordinal data were collected from participant perspectives to provide additional insight as well as to help make future improvements and sustain the use of FibroGuide in the routine care of patients with FM. Participant preference to receive health information directly from the provider signifies the importance that APRNs and other providers must collaborate with patients in the education and health technology process.

Advances in health technology have become more attractive to APRNs and patients to provide enhanced information that is not always available in the provider's office. Over the last decade, research has shown the benefits of health technology to patients with FM (Hebda & Czar, 2013). Although several studies reported patient satisfaction with obtaining health information from the Internet, many patients still preferred traditional face-to-face health education and instruction (Claugh & Casey, 2011; Korda & Itani, 2013; Palyo & Schopmeyer, 2012; Stinson et al., 2013). Results from this study concurred that participants (37.1%) preferred education directly from the provider. However despite the preference for face-to-face education, this study showed

that the FibroGuide technology is still beneficial for the management of FM. Moreover, the patient-focused EI framework allows APRNs to integrate the theory and evidence surrounding self-management and nursing informatics in order to sustain patient-focused quality care and outcomes (Knight & Shea, 2013).

### **Qualitative Data**

Six open-ended questions provided the DNP student a measure from the participants' perspective of the quality and value of FibroGuide as a health technology resource. Slightly less than 50% of the participants liked FibroGuide and thought the information would assist them in the self-management of FM. Finding time to use FibroGuide was the most-reported problem, followed by difficulty using the DVD-ROM. Interestingly, although 40% of participants said they supported FibroGuide, only 17.1% reported that they would continue to use it, even though the computer platform was ranked favorably (42.9%) as a means for receiving FM education. In addition, data from the activity log showed that communication, thinking differently, understanding FM, sleep, and pacing self were the modules participants used most often, supporting greater interest in function over symptoms.

Sustained improvements in physical function and self-management were demonstrated in the participants of this project using the health technology of FibroGuide. The use of an integrated self-management and health technology framework for patients with FM has application for APRNs in clinical settings where evidence-based nonpharmacological interventions have been slow to gain implementation (Williams et al., 2010). FibroGuide and other evidence-based technology programs have potential as

first-line approaches to the management of FM and other chronic conditions (Williams et al., 2010).

### **Dissemination and Utilization of the Results**

The purpose of dissemination is to relay the knowledge and experience from this project to APRNs, other health care providers, patients, and the public. The dissemination of the meaningful results from this study aims to share new perspectives and influence action and thinking by facilitating the science and art of nursing based on the current evidence to improve nursing practice and patient outcomes in the management of FM.

The FibroGuide capstone project was completed in a solo practice setting; therefore, to share this information the project and its results will be presented at various community health care settings, local nursing organizations, conferences, and workshops. Invitations to present an abstract of this project have been received from Terry Reilly Health Services and the Family Medicine Residency of Idaho. The Idaho Nurse Practitioner group requested an abstract after awarding the DNP student a scholarship for “evidence-based practices.” An abstract of this evidence-based project will also be submitted to the Idaho Board of Nursing for newsletter publication. The principal investigator for FibroGuide, David Williams, Ph.D., and the designers and developers for FibroGuide, Julie Bernardini and Susan Collins, will receive requested copies of the project abstract. Finally, it is important to disseminate this project to online peer-reviewed journals such as the *Journal of Issues in Nursing*, *Advance Registered Nurse Practitioner Care*, and the *Online Journal of Nursing Informatics*.

## **Limitations**

This paper represented an evidence-based project with preliminary descriptive findings suggesting that FibroGuide may improve self-management for patients living with FM. Several considerations were noteworthy when evaluating the merits of this project. First, there were a small number of participants evaluated in this project. Next, although the open-ended questions allowed for free responses, using a Likert-scale for rating may present a clearer description of the participant feedback. Third, the project was limited to a 12- week implementation period, which may have not allowed sufficient time for participants with a complex, chronic disorder to fully appreciate the value of FibroGuide. Lastly, a DVD-ROM can be more technically challenging for some to use compared to accessing an online website for their educational needs.

## **Conclusion**

FM is a complex and challenging disorder of unknown etiology; where the management of patients is less seen in specialty clinics and more often facilitated by APRNs in primary care and other health care settings. Furthermore, the management of FM is labor intensive, time consuming, and costly, and places high burdens on patients and health care providers. On the contrary, new simplified diagnostic criteria, updated primary care guidelines, and evolving health technologies have opened fresh opportunities for patients and APRNs gather and use health technology in the diagnosis and nonpharmacologic management of FM. Merging FibroGuide into the routine care for patient living with FM has application in the context of improved patient outcomes and patient-focused care where clinical practice has been slow to implement evidence-based nonpharmacologic strategies for FM.

## APPENDIX A

### FIBROGUIDE DVD-ROM



**A Self-management Program for People Living With Fibromyalgia.** As a person living with fibromyalgia, you know firsthand that fibromyalgia can be challenging. **FibroGuide** can show you how to help manage your symptoms.

#### Help from experts

**FibroGuide** is an interactive, customizable program that contains helpful information, tips, and resources, including expert videos and work sheets. These tools are based on key lifestyle strategies and skills that have been shown to help people with fibromyalgia manage their symptoms.

#### Help for people...

The **FibroGuide** program is based on the knowledge and experience of medical experts and patients, as well as evidence from research at the Chronic Pain and Fatigue Research Center at the University of Michigan.

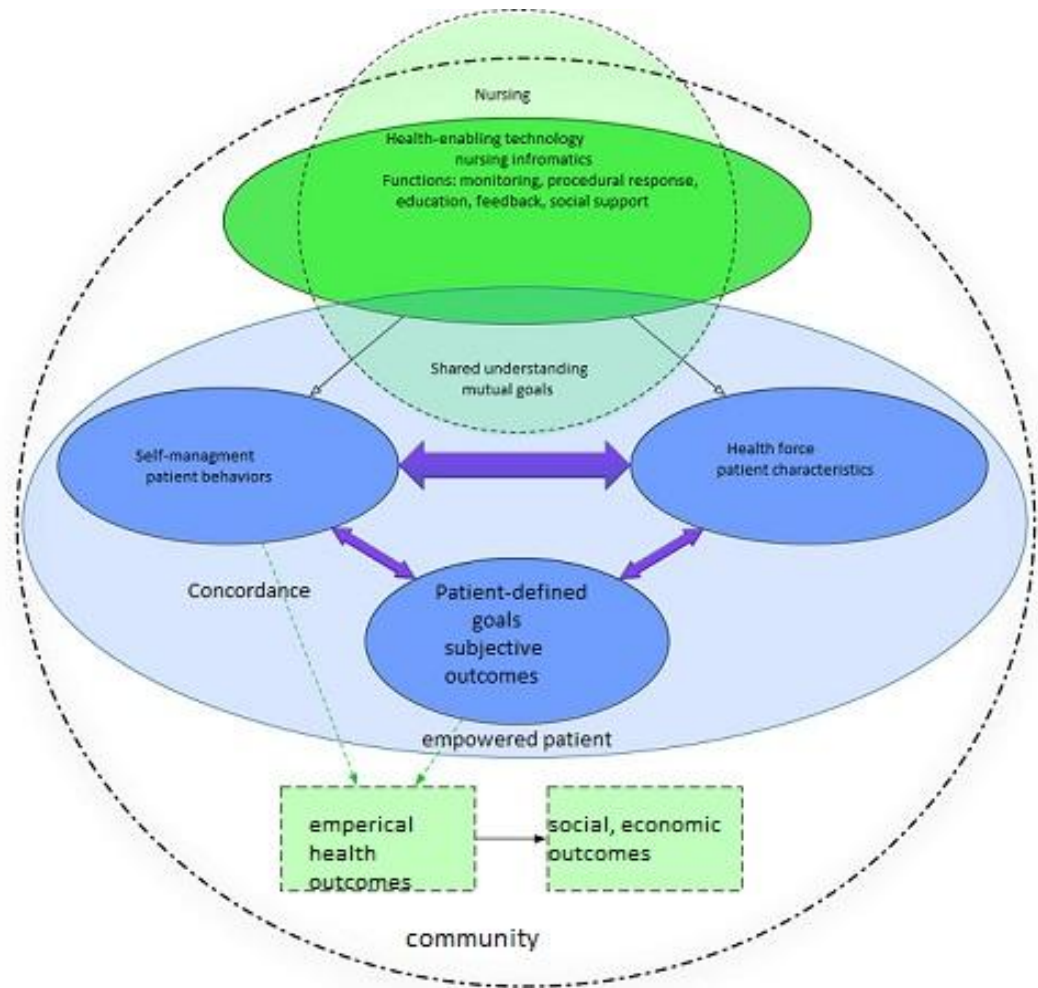
**Let FibroGuide help you better understand, track, and manage your fibromyalgia symptoms.**

[Get started now ▶](#)



## APPENDIX B

### THE EMPOWERMENT INFORMATICS FRAMEWORK



Self-management and informatics. Knight & Shea, 2013



**APPENDIX C**  
**SETTING WEBSITE**



**APPENDIX D**  
**CONSENT TO PARTICIPATE**



**Informed consent**  
**Department of Nursing**

**Title of Study: Merging Educational Technology into Routine Care for Patients Living with Fibromyalgia**

**Investigator(s): PI: Jennifer Kawi PhD MSN APRN FNP-BC CNE**

**Student: Toni Sparks APRN FNP-BC**

For questions or concerns about the study, you may contact Jennifer Kawi at 702 895 5930 or Toni Sparks at 208 333-0103.

For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted, contact **the UNLV Office of Research Integrity – Human Subjects at 702-895-2794, toll free at 877-895-2794 or via email at [IRB@unlv.edu](mailto:IRB@unlv.edu)**.

**Purpose of the Study** You are invited to participate in a research study. The purpose of this study is to implement FibroGuide, an evidence-based educational DVD-ROM endorsed by clinical practice guidelines as part of routine care for fibromyalgia. FibroGuide incorporates scientific evidence into a self-help patient education program designed to improve knowledge and self-management for fibromyalgia.

**Participants** You are being asked to participate in the study because you fit these criteria: adult age 18 or older, have a diagnosis of fibromyalgia or symptoms of fibromyalgia, currently under the care of Toni Sparks APRN FNP-BC, and do not exhibit behaviors or thoughts of self-harm or harm to others.

**Procedures** If you volunteer to participate in this study, you will be asked to do the following:

- Obtain a FibroGuide DVD-ROM provided by the office of Toni Sparks FNP PLLC (no cost)
- Complete an on-line demographic survey (approximately 5 minutes) and a Revised Fibromyalgia Impact Questionnaire (approximately 5 minutes)
- Use the FibroGuide DVD-ROM for at least 15 minutes a week over a 12-week period
- Log the date, time spent, and modules used from FibroGuide (15 minutes per week)
- After 12 weeks, you will complete another Revised Fibromyalgia Impact Questionnaire (approximately 5 minutes) and answer 6 open-ended questions (10 minutes)

**Benefits of Participation** There may be direct benefits to you as a participant in this study. We hope to learn that improving access to current research for fibromyalgia through FibroGuide will improve knowledge and self-management, thereby reducing symptom severity and improving overall function. However, participating in research does not guarantee benefits.

**Risks of Participation** There are risks involved in all research studies. This study may include only minimal risks similar to what would be encountered in a typical clinic visit. You may experience stress and discomfort from accessing the website and as a result of assuming a greater level of self-management of fibromyalgia.

**Cost /Compensation** There will not be any financial cost to you to participate in this study. The study will take 15 minutes per week of your time.

**Confidentiality** All information gathered in this study will be kept as confidential as possible. No reference will be made in online, written, or oral materials that could link you to this study. All materials/evaluations are done anonymously. All records and surveys will be stored in a locked facility at UNLV for 3 years after completion of the study. After the storage time, the information gathered will be destroyed.

**Voluntary Participation** Your participation in this study is voluntary. You may refuse to participate in this study or in any part of this study. You may withdraw at any time without prejudice to your relations with Toni Sparks ARNP FNP-BC or affect the health care you receive at the office of Toni Sparks PLLC. You are encouraged to ask questions about this study at the beginning or any time during the research study.

**Participant Consent:**

I have read the above information and agree to participate in this study. I have been able to ask questions about the research study. I am at least 18 years of age. A copy of this form has been given to me.

**By clicking on the links below, you confirm that you have read the information about the project and have been informed of its purpose and procedure, and agree to participate in this project.**

[IRB Demographic Survey](#)

[IRB Fibromyalgia Impact Questionnaire Revised](#)

[IRB Open-Ended Questions](#)

[IRB FibroGuide Activity Log](#)

Call us at 208-333-0103 or fill out our [online contact form](#).

**APPENDIX E**

**DEMOGRAPHIC SURVEY**

<a href="mailto:sabrina@biznov.com">sabrina@biznov.com</a>	Office of Tri S	<a href="mailto:fans@biznov.com">fans@biznov.com</a>	<a href="http://www.cffc.com">http://www.cffc.com</a>
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Gender:  Male  Female

In what year were you born?:

Relationship Status:  Single  Never Married  Married  Significant other  Widowed  Divorced  Separated

Education (highest completed level):

Employment Status:  Employed  Self-employed  Unemployed  Homemaker  Student  Retired  Unable to work/Disabled

Race/Ethnicity:  American Indian or Alaska Native  Black or African American  Native Hawaiian or Other Pacific Islander  White  Asian  Hispanic  Other

Do you own a computer or have access to a computer?  Yes  No

Do you have Internet access?  Yes  No

How many years have you been treated for fibromyalgia?

How many times a month do you use the Internet to look up information about fibromyalgia?

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**APPENDIX F**

**FIBROMYALGIA IMPACT QUESTIONNAIRE REVISED**

**(FIQR)**

**Duration of FM symptoms (years):**    **Time since FM was first diagnosed (years):**

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

Brush or comb your hair

**No difficulty**             **Very difficult**

Walk continuously for 20 minutes

**No difficulty**             **Very difficult**

Prepare a homemade meal

**No difficulty**             **Very difficult**

Vacuum, scrub or sweep floors

**No difficulty**             **Very difficult**

Lift and carry a bag full of groceries

**No difficulty**             **Very difficult**

Climb one flight of stairs

**No difficulty**             **Very difficult**

Change bed sheets

**No difficulty**             **Very difficult**

Sit in a chair for 45 minutes

**No difficulty**             **Very difficult**

Go shopping for groceries

**No difficulty**             **Very difficult**

**Sub-total** *(for internal use only)*

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

Fibromyalgia prevented me from accomplishing goals for the week  
**Never**            **Always**

I was completely overwhelmed by my fibromyalgia symptoms  
**Never**            **Always**

**Sub-total (for internal use only)**

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

Please rate your level of pain  
**No pain**             **Unbearable pain**

Please rate your level of energy  
**Lots of energy**             **No energy**

Please rate your level of stiffness  
**No stiffness**             **Severe stiffness**

Please rate the quality of your sleep  
**Awoke well rested**             **Awoke very tired**

Please rate your level of depression  
**No depression**             **Very depressed**

Please rate your level of memory problems  
**Good memory**             **Very poor memory**

Please rate your level of anxiety  
**Not anxious**             **Very anxious**

Please rate your level of tenderness to touch  
**No tenderness**             **Very tender**

Please rate your level of balance problems  
**No imbalance**             **Severe imbalance**

Please rate your level of sensitivity to loud noises, bright lights, odors and cold  
**No sensitivity**             **Extreme sensitivity**

**Sub-total (for internal use only)**

**FIQR TOTAL (for internal use only)**

# APPENDIX G

## ACTIVITY LOG

### Key for Modules

1= Understanding Fibromyalgia  
2= Communication  
3= Being Active  
4= Sleep  
5= Relaxation

6= What is Fibro Fog  
7= Setting Goals  
8= Pacing Yourself  
9= Thinking Differently  
10= Time for you

Date:	<input type="text"/>	Time (in minutes):	<input type="text"/>	Module (number):	<input type="text"/>
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## APPENDIX H

### SIX OPEN-ENDED QUESTIONS

What did you think about FibroGuide as part of your routine care?:

How do you think the information assisted in your self-management of your fibromyalgia?:

What barriers or challenges did you find using the FibroGuide DVD?

Do you plan to continue using FibroGuide as part of your routine care?

What do you think about using the computer to gain knowledge and management skills for fibromyalgia?

Rate your preference for health education (1 being the most useful and 5 being the least useful).

Internet/websites (rate 1-5)

DVD/video (rate 1-5)

Written (brochures/books)  
(rate 1-5)

Conversation with health care provider (rate 1-5)

Media (TV, radio, movies)  
(rate 1-5)

Reset

Submit



## APPENDIX I

### PERMISSION TO USE FIQR

---

Fibromyalgia Impact Questionnaire Revised (FIQR)      *Arthritis Research & Therapy* 2009, **11**:R120  
(doi:10.1186/ar2783)

This article is online at: <http://arthritis-research.com/content/11/4/R120>  
© 2009 Bennett *et al.*; licensee BioMed Central Ltd. This is an open access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/2.0>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Toni,

You have my permission to use the FIQR for your Doctorate of Nursing.

Please give reference to our 2009 original article and also our website at [www.figr.info](http://www.figr.info)

Robert Bennett, MD, FRCP, FACP, MACR  
Professor of Medicine



## APPENDIX J

### TIMELINE

TASK	ACTIVITY	START DATE	END DATE
Selected Committee Chair 1 SON 1 other (UNLV) department Completed/returned documents to Elizabeth Gardner	Emailed Jennifer Kawi Ph.D. Emailed Nancy Menzel Ph.D. Emailed Kendall Hartley Ph.D.	1/7/13	2/5/13
Reviewed literature Evaluated need Identified project	Literature review: FM, patient education, examined websites	1/15/13	3/15/13
Problem statement Purpose statement	E-mailed to Dr. Kawi	2/1/13	2/5/13
Revised proposal idea after conference call Developed objectives and goals	Reviewed literature for evidence and web-teaching for FM, CPG's & submitted corrected proposal to Dr. Kawi.	2/7/13	3/31/13
Identified measurement tools Developed budget Selected evidence-based website	Reviewed current literature for validity of tools, selected the Revised Fibromyalgia Impact Questionnaire (FIQR). Budget predicted to be low. Previewed 5 websites and selected FibroGuide.	3/10/13	4/15/13
Obtained permissions for project site, measurement tools, FibroGuide	FibroGuide has open access to public. FIQR (open access) Bennett et al., 2009. Setting owned by DNP student with full support from collaborative psychiatrist and staff.		10/13
Proposal date Revised proposal with new data and CPG's Reviewed draft	Emailed Dr. Kawi, Dr. Menzel, and Dr. Hartley	4/22/13	Confirmation 5/30
Proposal sent to committee Reviewed proposal draft from committee	Draft and finalized proposal Revised based on committee recommendations	6/1/13	6/10/13

PowerPoint presentation for proposal	Designed proposal PowerPoint, emailed to Dr. Kawi final paper	6/1/13	6/10/13
UNLV Proposal Defense with SON and graduate college extension approval	Contacted Elizabeth Gardner for extension to 6/17/13 Present @ UNLV		6/24/13
IRB	Completed application and submitted	June 2013	
Staff training (2 hours)	Introduced FibroGuide FIQR Outline of implementation Time frames Date collection	following IRB approval August 2013	8/2/13
Participant notification	Mailed, emailed, called eligible participants on the availability of FibroGuide	following IRB: August 2013	8/22/13
Participant orientation	Face to face, explained time frame, FIQR, access to FibroGuide, options for assistance, safety plan	following IRB- August 2013	8/22/13
Change FibroGuide website to DVD-ROM format	Submitted IRB modification for change to DVD-ROM	November 2013	Approved 11/23/13
Project implementation and maintenance	Monthly medication checks, weekly email reminder, and verification of participation	11/23/13	2/15/13
Project completed and final submission	Notified participants face-to-face, email. Repeat FIQR, open-ended questions	2/15/13	2/20/13
Report to chair	Provide updated document to Dr. Kawi		12/17/13
Data analysis	Generate report	February 2014	2/25/14
Final paper	Develop final paper	January 2014	3/7/14
Final paper	Submitted to Dr. Kawi	3/1/14	3/2/14
Final paper	Submitted to Dr. Menzel, Dr. Hartley	3/19/14	3/20/14
Defense	On-site UNLV, SON		4/7/14
Comply with final paperwork submission to graduate college			April 2014

## APPENDIX K

### PERMISSION TO COPY FIBROGUIDE

**From:** Susan Collins [S.Collins@surroundhealth.net]  
**Sent:** Monday, October 28, 2013 9:44 AM  
**To:** Toni Sparks  
**Subject:** RE: Follow up on FibroGuide request  
**Attachments:** report-lens.pdf

Hi Toni:

Thanks for the background – your research sounds so interesting. I am attaching a report we did on Healthcare Technology (it was a survey of healthcare extenders within SurroundHealth – an online community that HealthEd runs). The report aligns with your approach and the growing need.

Unfortunately, HealthEd only has 2 copies of the DVD– and I had sent you 1 of the 2. The easiest thing would be to have your DVD copied. If you Google “CD ROM duplication,” you should be able to find a service in your area.

I hope this helps,  
Susan

**APPENDIX L**  
**BUDGET**

FibroGuide Budget

Equipment/Supply	Quantity	Cost	Total
DVD-ROM	50	57.00	57.00
USB flash drive	3	18.00	18.00
Paper	50 sheets	2.00	2.00
Envelopes	50	23.00	23.00
Postage	40	43.00	43.00
Total			\$143.00

APPENDIX M

IRB APPROVAL



**Biomedical IRB – Exempt Review  
Deemed Exempt**

**DATE:** August 20, 2013

**TO:** Dr. Jennifer Kawi, School of Nursing

**FROM:** Office of Research Integrity – Human Subjects

**RE:** Notification of IRB Action

Protocol Title: A Web-Based Strategy as Part of Routine Care for Patients Living  
with Fibromyalgia  
Protocol # 1307-4515

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This memorandum is notification that the project referenced above has been reviewed as indicated in Federal regulatory statutes 45CFR46 and deemed exempt under 45 CFR 46.101(b)2.

**PLEASE NOTE:**

Upon Approval, the research team is responsible for conducting the research as stated in the exempt application reviewed by the ORI – HS and/or the IRB which shall include using the most recently submitted Informed Consent/Assent Forms (Information Sheet) and recruitment materials. The official versions of these forms are indicated by footer which contains the date exempted.

*Any* changes to the application may cause this project to require a different level of IRB review. Should any changes need to be made, please submit a **Modification Form**. When the above-referenced project has been completed, please submit a **Continuing Review/Progress Completion report** to notify ORI – HS of its closure.

If you have questions or require any assistance, please contact the Office of Research Integrity - Human Subjects at [IRB@unlv.edu](mailto:IRB@unlv.edu) or call 895-2794.

Office of Research Integrity – Human Subjects 4505 Maryland Parkway • Box 451047 • Las Vegas, Nevada 89154-1047 (702) 895-2794 • FAX: (702) 895-0805

## APPENDIX N

### IRB MODIFICATION APPROVAL



## Biomedical IRB – Exempt Review Modification Approved

### **NOTICE TO ALL RESEARCHERS:**

*Please be aware that a protocol violation (e.g., failure to submit a modification for any change) of an IRB approved protocol may result in mandatory remedial education, additional audits, re-consenting subjects, researcher probation, suspension of any research protocol at issue, suspension of additional existing research protocols, invalidation of all research conducted under the research protocol at issue, and further appropriate consequences as determined by the IRB and the Institutional Officer.*

**DATE:** November 18, 2013

**TO:** Dr. Jennifer Kawi, School of Nursing

**FROM:** Office of Research Integrity - Human Subjects

**RE:** Notification of IRB Action

Protocol Title: **Merging Educational Technology into Routine Care for Patients  
Living with Fibromyalgia**

Protocol #: 1307-4515

The modification of the protocol named above has been reviewed and deemed exempt. Modifications reviewed for this action include:

- Addition of 2 questions regarding computer use.
- Removal of Internet Impact Effectiveness questionnaire.
- Procedure revised to use FibroGuide DVD.
- Title changed to "Merging Educational Technology into Routine Care for Patients Living with Fibromyalgia".

This IRB action does not change your exempt status.

### **PLEASE NOTE:**

Upon approval, the research team is responsible for conducting the research as stated in the protocol most recently reviewed and approved by the IRB, which shall include using the most recently submitted Informed Consent/Assent forms and recruitment materials. The official versions of these forms are indicated by footer which contains the date deemed exempt. Should there be *any* change to the protocol, it will be necessary to submit a **Modification Form** through ORI - Human Subjects. No changes may be made to the existing protocol until modifications have been reviewed and a determination has been made by the ORI-HS and/or the IRB. Modified versions of protocol materials must be used upon final determination. Unanticipated problems, deviations to protocols, and adverse events must be reported to the ORI – HS within 10 days of occurrence.

Office of Research Integrity – Human Subjects 4505 Maryland Parkway • Box 451047 • Las Vegas, Nevada 89154-1047 (702) 895-2794 • FAX: (702) 895-0805

## REFERENCES

- Annemans, L., LeLay, K., & Taieb, C. (2009). Societal and patient burden of fibromyalgia syndrome. *Pharmacoeconomics*, 27(7), 547-59. doi: 10.2165/11313650-000000000-00000
- Arnold, L. M. (2010). The pathophysiology, diagnosis, and treatment of fibromyalgia. *Psychiatric Clinical Journal of North America*, 33, 375-408. doi: 10.1016/j.psc.2010.01.001
- Arnold, L. M., Clauw, D. J., & The FibroCollaborative. (2010). Fibromyalgia management: A framework for fibromyalgia for primary care physicians, 1-47.
- Arnold, L. M., Clauw, D. J., Dunegan, L. J., Turk, D. C., & The FibroCollaborative. (2012). A framework for fibromyalgia management for primary care providers. *Mayo Clinic Proceedings*, 87(5), 488-496. doi:10.1016/j.mayocp.2012.02.010
- Bailey, S. J., LaChapelle, D.L., LeFort, S.M., Gordon, A., & Hadjistavropoulos, T. (2013). Evaluation of chronic pain-related information available to consumers on the Internet. *Pain Medicine*, 14, 855-864.
- Bartleson, J. D. (2006). How to be sure your patient education is educating patients. Retrieved from: <http://www.aan.com/globals/assets/6106.pdf>.
- Bennett, R. M., Friend, R., Jones, K.D., Ward, R., Han, B. K., & Ross, R. L. (2009). The Revised Fibromyalgia Impact Questionnaire (FIQR): Validation and psychometric properties. *Arthritis Research & Therapy*, 11, 1-14. doi: 10.1186/ar2783



- Bodenheimer, T., Wagner, E.H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness. *Journal of American Medical Association*, 288(14), 1775-1779.
- Brown, T. M., Gard, S., Chandran, A. B., McNett, M., Siverman, S. L., & Hadker, N. (2011). The impact of “best-practice” patient care in fibromyalgia on practice economics. *Journal of Evaluation in Clinical Practice*, 18, 793-738. doi: 10.1111/j.1365-2753.2011.01678.x
- Camerini, L., Camerini, A.L., & Schulz, P.J. (2013). Do participation and personalization matter? A model-driven evaluation of an Internet-based patient education intervention for fibromyalgia patients. *Patient Education and Counseling*, 92, 229-234. doi: 10.1016/j.pec.2013.04.007
- Carlbring, P., Nilsson-Ihrfelt, E., Waara, J., Kollenstam, C., Buhram, M., Kaldo, V., ...Anderson, G. (2005). Treatment of panic disorder: Live therapy vs. self-help via the Internet. *Behaviour Research and Therapy*, (43), 1321-1333. doi: 10.1016/j.brat.2004.10.002
- Centers for Disease Control and Prevention. (2012). Fibromyalgia. Retrieved from <http://www.cdc.gov/arthritis/basics/fibromyalgia.htm>
- Chiauzzi, E., Pujol, L. A., Wood, M., Bond, K., Black, R., Yiu, E., & Zacharoff, K. (2010). Pain-Action-Back Pain: A self-management website for people with chronic back pain. *Pain Medicine*, (11), 1044-1058.
- Cross, C.L. (2014). Statistical analysis report. Las Vegas, NV: Cross
- Daraz, L., MacDermid, J.C., Wilkins, S., Gibson, J., & Shaw, L. (2011). The quality of websites addressing fibromyalgia: An assessment of quality and readability using

standardized tools. *British Medical Journal*, 1,1-8. doi: 10.1136/bmjopen-2011-000152

Dennis, N. L., Larkin, M., & Derbyshire, S. W. (2013). "A giant mess"- making sense of the complexity in the accounts of people with fibromyalgia. *School of Psychology*. doi: 10.1111/bjhp.12020

Fitzcharles, M. A., Ste-Marie, P. A., Goldenberg, D. L., Pereira, J. X., Abby, S., Choiniere, M., ... Shir, Y. (2012). Canadian guidelines for the diagnosis and management of fibromyalgia syndrome.

Fitzcharles, M. A., & Yunus, M. B. (2012). The clinical concept of fibromyalgia as a changing paradigm in the past 20 years. *Pain Research and Treatment*, 1-8. doi: 10.1155/2012/184835

Fitzcharles, M.A., Panopalis, P., Pereira, J., & Shir, Y. (2011). *The care gap in management of fibromyalgia: A needs assessment prompting the development of clinically relevant guidelines for the diagnosis, management and follow-up of patients*. Poster session presented at the meeting of the American College of Rheumatology, Chicago, IL.

Friedberg, F., Williams, D., & Collenge, W. (2012). Lifestyle-oriented nonpharmacological treatments for fibromyalgia: A clinical overview and applications with home-based technologies. *Journal of Pain Medicine*, 5, 425-435.

Garcia, J., Simon, M.A., Duran, M., Cancellor, J., & Aneiros, F.J. (2006). Differential efficacy of a cognitive-behavioral intervention versus pharmacological treatment

in the management of fibromyalgia syndrome. *Psychology, Health & Medicine*, 11(4), 498-506. doi: 10.1080/13548500600745286

Goldenberg, D. L. (2012). Dispelling myths: Evidenced-Based treatment of fibromyalgia: A collaborative approach to optimal care. Retrieved from <http://www.medscape.org/viewarticle/580428>

Goldenberg, D. L. (2009). *Clinical management of fibromyalgia*. Professional Communications, Inc. Caddo, OK.

Guagliardo, M.F. (2004). Spatial accessibility of primary care: Concepts, methods and challengers. *International Journal of Health Geographics*, 3(3), 1-13. doi:10.1186/1476-072X-3-3

Hebda, T., & Czar, P. (2013). *Handbook of informatics for nurses & healthcare professionals*. Saddle River, New Jersey: Pearson.

Hsu, M. C., Schubiner, H., Lumley, M. A., Stracks, J. S., Clauw, D. J., & Williams, D. A. (2009). Sustained pain reduction through affective self-awareness in fibromyalgia: A randomized controlled trial. *Journal of General Internal Medicine*, 25(10), 1064-1070. doi: 10.1007/s11606-010-1418-6

Kasper, S. (2009). The psychiatrist confronted with a fibromyalgia patient. *Human Psychopharmacal and Clinical Experimental*, (24), S25-S30. doi: 10.1002/hup.1027

Knight, E.P., & Shea K. (2013). A patient-focused framework integrating self-management and informatics. *Journal of Nursing Scholarship*, 00(0), 1-7. doi:10.1111/jnu.12059

- Koch, J., Andrew, S., Salamonson, Y., Everett, B., & Davidson P. M. (2010). Nursing students' perception of a web-based intervention to support learning. *Nurse Education Today*, 30, 584-590. doi: 10.1016/j.nedt.2009.12.005
- Korda, H., & Itani, Z. (2013). Harnessing social media for health promotion and behavior change. *Health Promotion Practice*, 14(1), 15-23. doi: 10.1177/1524839911405850
- Lee, T. T. (2006). Adopting a personal digital assistant system: Application of Lewin's change theory. *Journal of Advanced Nursing*, 55(4), 487-497. doi: 10.1111/j.1365-2648.2006.03935x
- Luciano, J.V., Sabes-Figuera, R., Caardenosa, E., Penarrubia, M.T., Fernandez-Vergel, R., Garcia-Campayo, J., ... Blanco, A.(2013). Cost utility of a psychoeducational intervention in fibromyalgia patients compared with usual care: An economic evaluation alongside a 12-month randomized controlled trial. *Clinical Journal of Pain*, 29 (8), 702-711.
- Marcus, D. A. & Deodhar, A. (2011). *Fibromyalgia: A practical guide*. New York, NY: Springer.
- Nihalani, N. D., Schwartz, T., & Chelbowski, S. (2006). Fibromyalgia: A review for the psychiatrist. *Psychiatry*, 44-60.
- Palyo, S. A., & Schopmeyer, K. A. (2012). Tele-pain management: Use of videoconferencing technology in the delivery of an integrated cognitive-behavioral and physical therapy group intervention. *Psychological Services*, 9(2), 200-202. doi: 10.1037/a0025987

- Pellise, F., & Sell, P. (2009). Patient information and education with modern media: The spine society of Europe Patient Line. *Euro Spine Journal*, 18(3), S395-S401. doi: 10.1007/s00586-009-0973-1
- Peterson, E.L. (2007). Fibromyalgia-Management of a misunderstood disorder. *Journal of the American Academy of Nurse Practitioners*, 19, 341-348. doi: 10.1111/j.1745-7599.2007.00235.x
- Queiroz, L.P. (2013). Worldwide epidemiology of fibromyalgia. *Current Pain Headache Report*, 17, 355-356. doi: 10.1007/s11916-013-0356-5
- Ramos-Remus, C., Salced-Rocha, A. L., Prieto-Parra, R. E., & Galvan-Villegas, F. (2000). How important is patient education? *Bailliere's Clinical Rheumatology*, 14(4), 689-703. doi: 10.1053/berh.2000.0107
- Reed, M., & Herrmann, M. (2012). The difficulties in developing and implementing fibromyalgia guidelines, new insights into fibromyalgia, Dr. William S. Wilke (Ed.). Retrieved from: <http://www.intechopen.com/books/new-insights-into-fibromyalgia/the-difficulties-in-developing-and-implementing-fibromyalgia-guidelines>
- Ritterband, L. M., Thorndike, F. P., Gonder-Fredrick, L. A., Mage, J. C., Bailey, E. T., Saylor, D. K., & Morin, C. M. (2009). Efficacy of an Internet-based behavioral intervention for adults with insomnia. *Archives of General Psychiatry*, 66 (7), 692-698.
- Rooks, D.S., Gautam, S., Romeling, M., Cross, M.L., Stratigakis, D., Evans, B, ... Katz, J.N. (2007). Group exercise, education, and combination self-management in

women with fibromyalgia: A randomized trial. *Archives of Internal Medicine*, 167, 2192-2200

Russell, I., J. (2006). Fibromyalgia syndrome: Presentation, diagnosis, and differential diagnosis. *Primary Psychiatry*, 13(9), 40-45.

Stahl, S. M., & Briley, M. (2009). Why psychiatrists should not ignore pain in their patients-focus on fibromyalgia? *Human Psychopharmacol and Clinical Experimental*, 24, S1-S2. doi: 10.1002/hup.1031

State of Idaho Department of Health and Welfare (2012). Idaho behavioral risk factor surveillance system (BRFSS). Retrieved from <http://healthandwelfare.idaho.gov/Health/VitalRecordsandHealthStatistics/tabid/1504/Default.aspx>

Stinson, J., White, M., Isaac, L., Campbell, F., Brown, S., Ruskin, D., ... Karim, A. (2013). Understanding the information and service needs of young adults with chronic pain. *Clinical Journal of Pain*, 00(00), 1-13.

U.S. Census Bureau. (2013). Population finder. Retrieved from <http://quickfacts.census.gov/qfd/states/16000.html>

U.S. Department of Health and Human Services (HRSA) (2013). Primary Medical Care HPSA Designation Overview. Retrieved from <http://bhpr.hrsa.gov/shortage/hpsas/designationcriteria/primarycarehpsaoverview.html>

U.S. Department of Health and Human Services. (2012). National institute of arthritis and musculoskeletal and skin diseases: Fibromyalgia. Retrieved from [http://www.niams.nih.gov/Health\\_Info/Fibromyalgia/default.asp](http://www.niams.nih.gov/Health_Info/Fibromyalgia/default.asp)

- Wells-Federman, C.L. (2000). Care of the patient with chronic pain: Part II. *Clinical Excellence for Nurse Practitioners*, 4(1), 4-12.
- Williams, D.A., Kuper, d., Segar, M., Mohan, N., Sheth, M., & Clauw, D.J. (2010). Internet-enhanced management of fibromyalgia: A randomized controlled trial. *Pain*, 151,694-702. doi: 10.1016/j.pain.2010.08.034
- Yonger, P. (2010). Internet-based information-seeking behavior amongst doctors and nurses: A short review of the literature. *Health Information and Libraries Journal*, 27, 2-10. doi: 10.1111/j.1471-1842.2010.00883.x

## CURRICULUM VITAE

### *Toni Sparks*

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#### EDUCATION

- 2012-2014 University of Nevada, Las Vegas  
Doctor of Nursing Practice
- 1997-1999 Idaho State University  
Master in Nursing; Family Nurse Practitioner
- 1988-1992 Boise State University  
Bachelor of Health Science-Nursing

#### PROFESSIONAL EXPERIENCE

- 2011-present: Owner of the Office of Toni Sparks PLLC  
Boise, Idaho  
Advance Practice Registered Nurse  
Family Nurse Practitioner  
Mental Health practice
- 2006-present: Office of Tim Ashaye MD  
Meridian, Idaho  
Advance Practice Registered Nurse  
Family Nurse Practitioner  
Mental Health practice
- 2011-present: Family Medicine Residency of Idaho  
Boise, Idaho  
Advance Practice Registered Nurse  
Family Nurse Practitioner  
Mental Health services in the HIV clinic
- 2010-2013: MidValley Health Care PLLC  
Meridian, Idaho  
Advance Practice Registered Nurse  
Family Nurse Practitioner  
Mental Health intensive outpatient



2002-2011: All Together Now

Boise, Idaho

Advance Practice Registered Nurse

Family Nurse Practitioner

Mental Health services, nonprofit case management agency

2006-2007: Omega Health

Boise, Idaho

Advance Practice Registered Nurse

Family Nurse Practitioner

Mental Health practice

2001-2007: Gem State Pediatrics

Meridian, Idaho

Advance Practice Registered Nurse

Family Nurse Practitioner

Mental Health services for pediatric population

2004-2006: Ascent Behavioral Health

Meridian, Idaho

Advance Practice Registered Nurse

Family Nurse Practitioner

Mental Health services, substance abuse program

1992-2004: Intermountain Hospital

Boise, Idaho

Advance Practice Registered Nurse & Certified psychiatric RN

Mental Health services, inpatient and outpatient

1995-2004: State of Idaho Department of H & W; Community Mental Health Clinic

Boise, Idaho

Advance Practice Registered Nurse & Certified psychiatric RN

Mental Health services, outpatient

## **CREDENTIALS**

ANCC Board Certified Family Nurse Practitioner

ANCC Board Certified Psychiatric RN

Idaho State Board of pharmacy; controlled substances

U.S. Department of Justice: DEA license

State of Idaho Designated Examiner

Clinical nursing preceptor: Boise State, Idaho State, Gonzaga, Stoneybrook

## **AFFILIATIONS**

American Nurses Association  
Idaho Nurses Association  
Idaho Medical Association  
American Psychiatric Nurses Association  
Nurse Practitioners of Idaho  
Neuroscience Education Institute  
Idaho Counsel Drug & Alcohol Dependency

## **PRESENTER**

ICADD: Outcomes for Dual Diagnosis  
Signs & Symptoms; understanding Schizophrenia  
State of Idaho Mental Health Conferences: Dual Diagnosis  
AIMS testing  
National Case Management Conference  
Astra Zeneca; speaker

## **COMMITTEES**

State of Idaho Demonstration/Enhanced Services Project  
Idaho Personnel Commission: Nursing Project  
State of Idaho Dual Diagnosis Task Force  
Ada County Detox Center  
Treasure Valley Nursing Vision  
Project Light

## **RECOGNITIONS**

124<sup>TH</sup> Medical Squadron: Air National Guard: Head Start Program  
Crisis Response; Suicide risk and aggressive behaviors  
Conflict Resolution and community medication  
Larry Schumaker: Excellence in Service  
State of Idaho: Honorable employee  
State of Idaho: Dual Diagnosis program research and development