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Continuing Education

Community-Based Care of the FIBROMYALGIA PATIENT

STRATEGIES TO PROMOTE SELF-MANAGEMENT

Along with a variety of distressing symptoms, a diagnosis of fibromyalgia (FM) brings with it substantial physical, psychosocial, and financial costs. Research shows that self-management is an effective means to manage FM and can lead to fewer healthcare visits. Yet due to the complexity of this disorder, healthcare providers need to be able to tailor treatment to individual patients by understanding effective treatment interventions. Home healthcare nurses (HHNs) are in a unique position to assess and implement effective treatment recommendations in the home setting and as such could consider incorporating self-management strategies into the home visit with the FM patient. Therefore, the purpose of this article is to use a case study to describe the assessment of FM patient's functional ability and quality of life and how the HHN may integrate self-management teaching into the established home care visit. A review of the literature and discussion of self-management interventions for the FM patient is presented. A summary of the case study and proposed clinical implications is offered.

Fibromyalgia (FM), a chronic widespread pain (CWP) disorder with no clear pathologic cause and no known cure (Menzies, 2016), is the second most common rheumatologic disorder after osteoarthritis (Clauw, 2015). FM can affect children, adolescents, and men but is most frequently reported in women, with prevalence estimates ranging from 3 million to 5 million in the United States (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2014; Starkweather & Menzies, 2016). In addition to CWP, patients diagnosed with FM experience a variety of distressing symptoms, including fatigue and depression. Other reported symptoms noted to interfere with an individual's ability to live a good quality of life are nonrestorative sleep, morning stiffness, and cognitive disturbances (Arnold et al., 2016). Disabling features of FM include physical and psychological distress, decreased ability to perform activities of daily living, and loss of work productivity. A diagnosis of FM brings with it substantial physical, psychosocial, and financial costs, with research showing there is an increased disease burden among FM patients as compared to those patients with CWP without a diagnosis of FM (Arnold et al., 2016; Schaefer et al., 2016). This may be evidenced by reported annual expenditures of approximately $12 to $14 billion related to the diagnosis and treatment of FM (National Fibromyalgia & Chronic Pain Association, 2016). Combined, the physical, economical, and emotional consequences of living with FM presents a significant burden to individuals, their families, and to society as a whole.

Living with FM on a daily basis, then, has its challenges. Women have reported the symptoms of FM as variable, unpredictable, and distressingly invisible, with an outcome that puts a significant burden on their family members (Cunningham & Jillings, 2006). Unfortunately, when one symptom manifests itself, oftentimes it exacerbates another symptom, hence making the symptom management difficult. An interpretive descriptive study

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by Cunningham and Jillings described what individuals living with FM report:

> *It's not just the pain and the fatigue, ...it's the nonrestorative sleep…it's a vicious cycle because if you don't get enough sleep you feel pain more acutely…you're more tired and unable to sleep well" and "…Fibromyalgia is one of the most irrational illnesses … I do get depressed because when you wake up in the morning, you can't get up. Doesn't make sense, you know, so fibromyalgia does affect the mental health and the well-being (p. 262).*

These researchers identified a recurring theme that "medical advice regarding treatment and therapy options was often ineffectual in the face of FM's apparent illogic" (p. 264) and therefore they stressed the important role nurses have in individualized and comprehensive assessment and care.

Disabling features of fibromyalgia include physical and psychological distress, decreased ability to perform activities of daily living, and loss of work productivity.

Self-Management and Home Healthcare Nurses

Home healthcare nurses (HHNs) contribute to enhanced patient care by conducting assessments to identify symptoms such as chronic pain, which, when left untreated, can lead to limited function and decreased quality of life. Self-management strategies, combined with patient support and education from healthcare providers, have been shown to help patients cope with managing symptoms that may accompany chronic illnesses, including pain, fatigue, and decreased physical activity and function (Kengen Traska et al., 2012; Sparks et al., 2016; Vanderboom et al., 2014). HHNs are in a unique position to enable patients to manage such symptoms through education and support that would include teaching self-management strategies tailored to the individual patient. This may result in better health outcomes and quality of life, potentially leading to decreased use of health-related services (Ryan & Sawin, 2009). In an effort to contribute to fundamental nursing knowledge related to assessing and developing a patient care plan framed around a self-management protocol for the patient with FM, we conducted a literature review and present a case study narrative.

Literature Review

An extensive review of the literature in the PubMed database revealed a total of three articles written within the last 5 years that addressed FM patients, nurses, home healthcare, and self-management techniques. Key words were searched individually and then combined using Boolean operators and included: "nurse," "nurse role," "home health," "self-management," "quantitative," "qualitative," and "fibromyalgia." A review of these three articles revealed two major themes regarding symptom self-management in persons diagnosed with FM: (1) patient education and (2) health information technology as relevant to self-management strategies for symptom management in patients diagnosed with FM.

Patient Education

In a descriptive qualitative study that included eight women diagnosed with FM, study participants were asked a series of interview questions related to self-management of their symptoms (e.g., "What strategies do you use to get through a bad day with FM?" [Kengen Traska et al., 2012, p. 628]). Patient reports of symptoms included "I'm in so much pain, I can't move and this means I can't cook dinner, or I'm not sure to make the bed today" (p. 629). Regarding levels of fatigue, another research participant stated she felt "… like I weigh twice as much as I weigh…I'll lay down on the couch and… I just can't do anything" (p. 629). The authors pointed out that FM patients seemed to report a variety of symptom experiences, and suggested that nurses should consider the biopsychosocial approach to symptom management. They further suggested nurses consider how "…to assist persons with FM to become active in learning about their own responses and in making choices about how to live their lives as well as possible" (p. 633). In this way, nurses can make teaching self-management techniques truly patient-centered. It is important to note that a new finding from this study was the identification of extreme sensitivity to touch and the role this plays in determining which self-management behaviors may be reasonably adapted for and by this patient population. Treatment options must be carefully considered if patients with FM are to avoid becoming unnecessarily homebound without the ability to independently complete activities of daily living (ADLs). The authors concluded that, with education and support, it may be possible for FM patients to develop successful strategies for coping with chronic pain and fatigue.

Health Information Technology

Health information technology (HIT) may also be an effective teaching strategy for patients to learn self-management skills and techniques (Sparks et al., 2016; Vanderboom et al., 2014). For example, Sparks et al. conducted a nonexperimental observational pilot study in which 35 individuals diagnosed with FM (n = 3 male; n = 32 female) participated in a 12-week HIT self-management intervention for purposes of improving functional status and ADLs as measured by the revised Fibromyalgia Impact Questionnaire-Revised (FIQR) (Bennett et al., 2009). Study participants were assigned to use the FibroGuide (Williams et al., 2010), an HIT platform comprised of 10 evidence-based modules, for at least 15 minutes per week. The FibroGuide is focused on education about FM and includes self-management modules, for example, improving sleep, making time for self, and relaxation strategies (Sparks et al.). Although the pre- and posttest FIQR scores were reported as statistically significantly improved (p = 0.017), indicating that functional status had improved, the authors noted that "many participants still preferred receiving health information directly from their healthcare providers" (Sparks et al., p. 59).

In a descriptive study to determine the feasibility of adding HIT self-management support for symptom monitoring as adjunctive care in a sample of N = 20 women diagnosed with FM, Vanderboom et al. (2014) asked study participants to rate symptoms of pain, fatigue, and physical activity on mobile monitoring devices three times daily for 7 consecutive days. As part of the study protocol, participants received either a telephone call or an email from a study-related nurse whose task was to encourage use of coping strategies and symptom management that had been learned as part of a prior outpatient 4-month FM treatment program (not described by the authors nor reported in the literature)

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Evidence-based recommendations support nonpharmacological therapy as first-line therapy for symptom self-management, including strategies such as aerobic and strengthening exercise, cognitive behavioral therapy, meditative movement therapies, and mindfulness-based stress reduction.

(Vanderboom et al., p. 559). The authors reported that 65% (n = 13) of the study participants noted that the HIT intervention contributed to an enhanced ability to self-manage their symptoms of pain, fatigue, and decreased activity, provided them with a sense of having greater control over their symptoms as well as facilitating easier access to their healthcare team. Taken together, both Sparks et al. (2016) and Vanderboom et al. found that not only do HIT interventions contribute to enhanced self-management strategies in the FM patient population, but the results of these studies suggest the importance of the nursing role.

In summary, the research literature supports the supposition that self-management strategies may be effective in symptom management for FM patients whether through patient education or HIT. In either case, it appears that patients desire, need, and benefit from patient education efforts, whether through HIT or through direct contact with their healthcare team. HHNs are in a unique position to teach and reinforce self-management skills in the home setting to patients with FM. In that light, patient care has the potential to be enhanced when HHNs seek the use of evidence-based literature. To complement this understanding, we provide a case study overview description, suggest a nursing process, propose an intervention, and discuss clinical implications related to the home healthcare of the FM patient.

Case Study Overview

Care of the FM patients in the home by HHN may or may not be reimbursed, depending on the insurer. Reasons that care may be covered is if the FM patient has a comorbid condition that warrants a skilled care home visit or a transition from hospital or other medical facility to home that requires intervention such as home safety evaluation, medication reconciliation, or specific nursing care (Medicare Interactive, 2017). However, the patient may not be able to focus on the health problem at hand when FM is not adequately controlled. Therefore, although the referral may not be specifically for FM, as this case study suggests, the HHN who has been educated on the importance of self-management skills could integrate patient education into an approved home visit.

The purpose of using this case study is to identify and explain self-management techniques that can be incorporated into the care plan of a patient with FM and highlight assessment tools that the HHN can use to measure severity of symptoms and track the patient's response to the self-management intervention. Three of the most valuable tools are (a) the Katz ADL (Katz et al., 1970) to determine basic ability to complete self-care tasks (scores range from 0 to 6 with higher scores indicating greater level of independence); (b) PHQ-9 (Kroenke et al., 2001) to assess for presence and level of depression (scores range from 0 to 27 with higher scores indicating higher levels of depression); and (c) the FIQR (Bennett et al., 2009) to determine the impact on function and ability that FM is having on the patient (scores range from 0 to 100 with higher scores indicating a higher level of difficulty with activities). There are several important things that make the FIQR assessment tool particularly valuable in that it: (1) assesses three different domains (e.g., function, overall impact, and symptoms); (2) discriminates between patients with FM, rheumatoid arthritis, systemic lupus erythematosus, and major depressive disorder; and (3) requires less than 2 minutes to complete and is easy to score (Bennett et al.). These three assessment tools can provide evidence of the patient's baseline health status and can then be used to evaluate the effectiveness of a nursing intervention.

Psychosocial Assessment

RT is a 65-year-old female who lives at home and is the primary caregiver for her 20-year-old son who has cerebral palsy. She has no other family members living locally. She receives Social Security as her main source of income and has Medicare coverage for health insurance. RT states she has spent the last 3 years seeking healthcare treatment to determine the cause of her constant pain and fatigue, which she reports has been extremely debilitating. After visiting six different primary care physicians (PCP) and having multiple hospitalizations seeking relief, she was recently diagnosed by her PCP with FM using the modified ACR 2010 criteria of assessing widespread pain and symptom severity that has been present for at least 3 months and is not attributed to another disorder that would explain the pain (Wolfe et al., 2010; 2011). Her PCP provided her with an information pamphlet on living with FM and sent her home on a combination of Gabapentin 300 mg PO twice a day (modulates neurotransmitter release) and Tylenol Extra Strength 1–2 tablets PO every 6 hours as needed for pain (not to exceed 4 g/day). After starting the medications, RT reported a 3-month period of improved symptoms. She expressed relief just to have a diagnosis for her symptoms and stated she was happy that "someone is finally listening to my concerns."

About 3 months after this initial diagnosis, RT's son called emergency medical services (EMS) to report he could not get his mother out of bed. When EMS arrived, RT appeared moderately disoriented, disheveled, reported having severe abdominal pain, and was transported to the emergency department (ED) where she was diagnosed with acute appendicitis. She was admitted to the hospital for open appendectomy surgery and had a nasogastric tube placed for 24 hours after the surgery. While RT was hospitalized, the healthcare team expressed concern about RT's lack of social support, observable signs of depression, deconditioning, and were also concerned with her ability to continue as primary caregiver for her son who had a physical disability. Once it was determined that RT was tolerating oral intake, she was discharged home with an HHN consult for care coordination services including wound care, home safety evaluation, and medication reconciliation.

Physiological Assessment

During the initial HHN visit, RT is sitting on her couch reporting that she isn't feeling well today due to the chronic pain and fatigue. She has been unable to leave her home to go to the store or prepare her own meals. Her home is clean and well organized. She is well groomed, alert and oriented, and her vital signs are stable. She has a flat affect, answers questions appropriately but with little expansion. She reports a >10% weight loss over the past 6 months. One of her son's friends has been bringing meals to the house five times a week and does most of the grocery shopping.

When assessing RT's functional level, she scores a 4/6 on the Katz ADL Scale due to an inability to get herself in and out of the shower and reports being incapable of dressing herself without assistance from her son. She scores 75 on the revised FIQR, as she reports a high level of difficulty with daily activities, a significant impact on her ability to accomplish personal goals, and an inability to manage symptoms. RT's PHQ-9 score is 17, indicating moderately severe depression.

Medication reconciliation reveals she has a stockpile of medications from different providers that she states she keeps "just in case my pain gets too bad and I can't get to the doctor." RT reports that she has been unable to go to the pharmacy so her son has been picking up her prescriptions from the drugstore across the street, which presents a safety concern due to his disability. Additionally, she reports taking 600 mg of ibuprofen every 4 to 6 hours around the clock.

Nursing Diagnosis

Despite her noted challenges, RT expresses a desire to "get better again and feel as good as I used to feel." When asked what her goal of treatment is, she states "I want to be able to take care of myself and my son independently again. I want to know I can go to the store and cook all of our meals." Therefore, her identified nursing diagnosis is self-care deficit related to pain and chronic fatigue as evidenced by inability to perform or complete ADLs for self. The HHN identified that her stated goals would help her in a variety of ways. For example, if she can improve her food security she will be able to eat more nutritiously that will result in improved healing. If she can better manage her pain, she will have improved mobility and enhanced ability to complete ADLs independently.

Planning Phase

The planning phase is based on the self-management theory and it includes three main components. The first component is process, defined as use of self-regulation skills to manage chronic conditions. The second component is program, defined as identification of interventions designed by healthcare professionals to educate individuals in managing their chronic illness. The third component is outcomes, which are achievements of the health benefits desired and agreed upon by both the patient and the provider (Ryan & Sawin, 2009). In consideration of RT's case study, the HHN will integrate process and outcome to design the self-management program in concert with RT. With this plan of care, RT will be more prepared to assume responsibility for managing her own health.

Outcomes

Outcomes are set with the goal of helping RT stabilize her health condition. The following outcomes are based on the described self-management theory framework and were agreed upon by her and the HHN.

By the end of the 8-week Self-Management protocol RT will:

1.) Identify her level of self-care
2.) Identify her self-care deficits
3.) Identify strategies to enhance self-care
4.) Set personal goals
5.) Demonstrate one or two self-care strategies
6.) Evaluate the effectiveness of her self-care strategies weekly

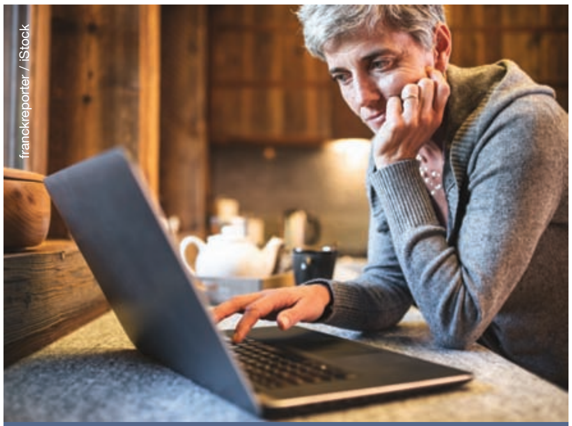
Proposed Program Intervention

After the initial assessment, the HHN and RT develop a plan together based on the self-management theory. The nurse initiates a 2-month 8-week protocol with weekly visits. The goal is to provide RT with self-management strategies to help RT recapture some basic function and independence that will ultimately improve her quality of life. The HHN will promote health literacy, support new sense of self within the context of managing a chronic illness, conduct symptom assessments, prevent exacerbation of symptoms so that rehospitalization (or ED use) is not necessary, and discuss self-management techniques.

Box 1. Additional Resources

- University of Michigan's Chronic Pain and Fatigue Research Center http://www.med.umich.edu/painresearch/patients/self.html
- U.S. Department of Health and Human Services: "Self-Management Support" https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/self/index.html
- National Fibromyalgia and Chronic Pain Association http://www.fmcpaware.org/resourceseducation/self-management-of-chronic-pain-symptoms2.html
- National Institute of Arthritis and Musculoskeletal and Skin Diseases https://www.niams.nih.gov/health_info/Fibromyalgia
- National Data Bank for Rheumatic Diseases https://www.arthritis-research.org/research/fibromyalgia-criteria
- CDC Fact Sheet https://www.cdc.gov/arthritis/basics/fibromyalgia.htm

When designing a self-management program for an FM patient, the HHN can refer to the skills and techniques listed at the University of Michigan's Chronic Pain and Fatigue Research Center (2017; http://www.med.umich.edu/painresearch/patients/self.html). This HIT resource is easy to access and offers a patient-friendly website. The patient-centered topics specific to FM include stress management education, problem solving, communication skills, relaxation techniques, pacing, sleep concerns, memory tools, and physical activity suggestions. Therefore, when setting goals with RT, part of the educational component would be to introduce her to this HIT resource. By demonstrating to RT how to access and use the website, the HHN is modeling learned behavior and encouraging RT to act independently. For example, drawing upon this HIT resource, RT and the HHN could perhaps select physical activity to help enhance RT's quality of life. It has been suggested in the research literature that patients who self-engage in physical activity may have improved symptoms of depression; however, patient perceptions of engaging in physical activity need to be taken into consideration when designing the self-management program (Searle et al., 2011). See Box 1 for other patient resources.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Health information technology (HIT) may also be an effective teaching strategy for patients to learn self-management skills and techniques.

Considering these suggestions, the HHN would assess RT's current physical ability, current symptom complaints, and her perceptions related to engaging in physical activity. With this information in hand, the HHN would explore the type of physical activity in which RT may be willing to engage at that moment, with hopes that physical activity may incrementally be integrated into RT's daily lifestyle along with other possible modalities as proffered by the HIT resource website noted. Although we focus on physical activity as one nonpharmacological approach that can be used by the HHN to help RT self-manage her symptoms, the suggested HIT resource site offers a variety of nonpharmacological approaches that may be considered by FM patients. This multimodal approach in the self-management of FM is supported by a recent systematic review of evidence-based practices for pharmacological/nonpharmacological management of FM (Macfarlane et al., 2017). Evidence-based recommendations support nonpharmacological therapy as first-line therapy for symptom self-management, including strategies such as aerobic and strengthening exercise, cognitive behavioral therapy, meditative movement therapies, and mindfulness-based stress reduction. In keeping with the theme of promoting self-management, other resources that RT and the HHN may access could include: the Department of Health and Human Services (https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/self/index.html); Centers for Disease Control and Prevention (https://www.cdc.gov); nonprofit organizations such as the National Fibromyalgia and Chronic Pain Association (http://www.fmcpaware.org/resourceseducation/self-management-of-chronic-pain-symptoms2.html); as well as community service boards.

Discussion and Clinical Implications

Assuming a patient initiates and remains fully engaged in a self-management program, the HHN would expect to see improved assessment scores related to the patient's ability to function. In the case of RT, if she were to remain engaged in the self-management program, positive outcomes could include improved physical function, pain management, and decreased signs of depression. For example, it may be possible that RT's Katz ADL scores would increase from 4 to 6 that would indicate functional independence. In the case of depression, PHQ-9 scores could decrease from 17 to a score as low as 10, indicating RT may be better managing her depression. Finally, the FIQR score could lower from 75 to 45, suggesting that her ability to manage FM symptoms is improving.

These potential positive outcomes for RT have some support in the literature. For example, Oh et al. (2010) and Oh et al. (2012) established the importance of determining patient characteristics as potential predictors of postintervention outcomes in persons diagnosed with FM. In a 2010 study, Oh et al. administered a 1.5-day FM self-management intervention to individuals ($N = 521$; $n = 22$ male; $n = 499$ female) diagnosed with FM. The intervention included education about FM, cognitive behavioral techniques for coping with stress and improving sleep, education in pacing the day's activities, and importance of an exercise program and time management. The authors measured participant's ability to manage FM symptoms by administering the FM impact questionnaire at preintervention and 6 and 12 months postintervention. Their study purpose was to determine long-term effectiveness of the intervention. The authors found that participants reported improved symptom management and enhanced quality of life at 6 and 12 months, thus suggesting the treatment program had a sustained benefit (Oh et al., 2010, p. 120). In a secondary analysis of the 2010 data, Oh et al. (2012) explored which patient characteristics may have been predictive of these outcomes. The authors reported that those individuals in the original study £40 years of age, who reported lower tender point counts, had no history of abuse, higher baseline depression scores, and a higher level of education (e.g., college or graduate degree) were found to be more likely to respond positively to the self-management intervention over time. It would seem therefore the HHN caring for persons like RT may consider combining patient characteristics, patient education, and HIT resources to provide a comprehensive self-management nursing intervention in the community setting.

Conclusion

Care of FM patients in the home care setting carries with it an inherent complexity. Further confounding the complexity of care are inadequate resources in the literature to inform HHNs in the support of FM patients. It is understood that FM patients suffer from decreased quality of life when symptoms are poorly managed. The purpose of this case study was to provide evidence-based information related to self-management tools in the care of patients with FM with the goal of empowering the HHN to integrate these resources into her or his patient-centered care of this vulnerable patient population. However, as a caveat to the importance of enhanced patient care, we suggest that although self-management protocols are available through HIT resources and research evidence demonstrating the effectiveness of using self-management strategies in persons with FM is limited, individuals with FM may discover or develop their own self-management strategies. Although not evidence-based but because such strategies may be uniquely suited to each individual's lifestyle and temperament, the HHN may find that such personalized strategies may very well be equally as effective as current evidence suggests.

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Community-Based Care of the Fibromyalgia Patient: Strategies to Promote Self-Management

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