Implementation of an epilepsy self management protocol in an outpatient neurology clinic

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Implementation of an Epilepsy Self Management Protocol in an Outpatient Neurology Clinic

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Abstract

It is essential that patients with epilepsy receive educational information about their disease and its management, but there is dissatisfaction with the education received. The purposes of this evidence-based project were to examine the current knowledge level and disease management behaviors of epilepsy patients in an outpatient clinic and to measure the effectiveness of implementing a self-management protocol using the Epilepsy Self Management Scale (ESMS). Pender's health promotion model and Rogers’ diffusion of innovation theory were used to guide the development and completion of this project. An evidence based epilepsy self-management protocol was developed and implemented at an outpatient neurology clinic by an interprofessional clinic team that consisted of: a) evaluation of self management behaviors (Epilepsy Self Management Scale (ESMS)): b) individual education using the ESMS and developed resources: c) follow up phone call; and d) measurement of the outcomes of the self management protocol (patient self-management (ESMS) and process). Twenty patients participated in all or portions of the protocol. Scores on the ESMS increased from pre to post implementation of the protocol ($t = -2.67$). Identified as the most difficult self-management areas were seizure management and information management. Recommended changes in protocol implementation include adding information about safety measures such as medical alert bracelets and driving to the educational packets. Follow up phone calls were discontinued due to difficulties reaching patients. The results of this study suggest that the ESMS is an acceptable tool for evaluating patients’ self management behaviors. Epilepsy self management protocols need to include both verbal and written educational materials. Educating epilepsy patients about positive self management behaviors may lead to better health outcomes.
Introduction and Statement of the Problem

Epilepsy is one of the most common neurological disorders in the world. It affects people of all ages, races, and ethnic groups (Chang & Lowenstein, 2003). Approximately 3 million people in the United States have been diagnosed with epilepsy, and an additional 10 percent of the U.S. population will likely experience at least one seizure in their lifetime (Chang & Lowenstein). A diagnosis of epilepsy is given to individuals who have experienced two or more unprovoked seizures (Chang & Lowenstein; Leppik, 2007). Epilepsy is considered a chronic health condition. One half of the individuals living in the United States currently are burdened by long-term health conditions (Jerant, von Friederichs-Fitzwater & Moore, 2005; Lau-Walker and Thompson, 2009), making epilepsy one of the nation’s leading neurological disorders.

All patients with chronic conditions need both educational and psychosocial support in order to better understand and manage their disease. In particular, patients need educational and psychosocial support that fosters improved self-management. Specifically pertaining to epilepsy, Robinson et al. (2008) have defined “self-management” as “a class of adaptive behaviors used by persons to control their seizures” (p. 523). More than 20% of patients with epilepsy continue to have breakthrough seizures even while taking anti-epileptic medications (AEDs), which suggests that patients need to increase their knowledge, improve their self-management skills, and modify their healthcare behaviors in order to reduce seizure frequency and improve quality of life (Robinson et al.).

Epilepsy patients appreciate receiving educational information; however, they have frequently indicated dissatisfaction with the amount of time spent with and the quality of information provided to them by healthcare practitioners (Doughty, Baker, Jacoby & Lavaud, 2003). Risdale, Morgan, and O’Connor (1999) found that epilepsy patients receiving an
educational intervention perceived physicians as too busy to teach them about their disease and how to manage it. However, these same patients perceived nurses as having adequate time and expertise to educate them about epilepsy and the management of epilepsy. Participants indicated they believed that seeing a nurse when they first were diagnosed with epilepsy would have been more beneficial (Risdale et al.).

Epilepsy is a chronic health problem (Barkley, 2003; DiLorio, Shafer, Letz, Henry et al., 2004; DiLorio, Shafer, Letz, Henry, Schomer et al., 2006), but evidence suggests that people with epilepsy are not receiving adequate educational support from their health care providers (DiLorio, Shafer, Letz, Henry et al., 2004; DiLorio, Shafer, Letz, Henry, Schomer et al., 2006). Patients with epilepsy need to understand their disease, and they need to develop and maintain the skills to manage it (Kendall, Thompson & Couldridge, 2004). Patients who fail to understand their disease and effective ways of managing it are far more likely to experience adverse health outcomes than patients who understand and manage their disease well (May & Pfafflin, 2002; Carreno, Vyhlímeš, Grau, & Ivanovic, 2006). It is evident from the literature (DiLorio, Faherty et al., 1992; DiLorio, Henry et al., 1995; Kendall, Thompson & Couldridge, 2004;) that improving patients’ knowledge about their epilepsy will positively influence their self-efficacy and ability to manage their disease, thereby improving their symptoms and prognoses. The objective of this evidence-based project is to identify, understand, and increase the knowledge level of epilepsy patients who receive treatment at the University of Toledo Neurology clinic.

Current practice at the UT Epilepsy Outpatient Clinic includes examination by a neurologist and, in some cases, by a medical student or a resident physician. For new patients, examinations typically range from 30 to 45 minutes, and include minimal time for educational intervention. All new patients diagnosed with epilepsy are provided an educational folder
containing information about clinic hours; important phone numbers; medications; and lifestyle management issues, such as driving and exercise. Depending on the physician, the patient schedule, and the workload, the information may or may not be reviewed with the patient during the clinic visit. New patients typically do not interact with any educational nursing staff members during their initial patient appointment. Rather, new patients are given an educational folder that contains articles and pamphlets, but patients are provided minimal explanation and limited opportunities for interaction.

For this evidence-based project, all new patients received the Self-Management of Epilepsy Protocol created by the author. The participants completed the Epilepsy Self-Management Scale (ESMS) survey (DiIorio, Faherty et al., 1992) to assess their current understanding of epilepsy and their self-management abilities. After completing the survey, patients participated in an educational session with a nurse or nurse practitioner. During this educational session, the nurse practitioner (NP) or registered nurse (RN) educated the patients by reviewing their survey answers and the educational sheet with them. The nurses answered any questions posed by the patients or caregivers. Phone contact was made following their appointment, and a second ESMS was administered and completed by participants a few weeks later.

**PICO Question**

The problem statement and research question for this research project were developed by using the PICO heuristic (population of interest, intervention, comparison, and outcome). The PICO question is as follows: Does implementing an epilepsy self-management protocol with UT neurology clinic patients increase their self-management abilities when compared to the current standard of care?
Summary

Being diagnosed with epilepsy can have far-reaching physical and psychosocial effects that are just as or more difficult to deal with than having a seizure (Couldridge, Kendal, & March 2001; MacDonald, Torrance, Wood, & Womersley, 2000). Having increased knowledge about epilepsy and improving self-management behaviors are important factors in improving one’s ability to effectively cope with epilepsy and to minimize the illness’s impact on physical and psychosocial functioning (Doughty, Baker, Jacoby, & Lavaud, 2003). The Living Well with Epilepsy Conference (Barkley, 2003) reported that self-management needs to be an area of focus, but due to lack of accessibility, lack of availability, and lack of insurance coverage, many patients with epilepsy do not have access to educational and support programs.

Theoretical Framework

Knowledge

The first phase is the knowledge phase. During the knowledge phase of the diffusion of innovations theory, researchers identify a clinical problem and conduct background research to locate and evaluate supporting evidence for a solution (DiCenso et al., 2005). For the present project, the author conducted a review of the literature focusing on the impact of epilepsy patients’ knowledge on epilepsy management. The author used the following search terms: epilepsy, social support, self efficacy and self management. Research conducted by DiIorio, Faherty et al., 1992; DiIorio Hennessey, et al., 1996; DiIorio, Shafer, Letz, Henry, Schomer et al., 2004) identified a positive correlation between self-efficacy and self-management in patients with epilepsy. In fact, research has suggested that patients with increased knowledge about their disease will feel more capable of performing self-management behaviors and thereby experience improved health outcomes and higher-quality living (Cochrane, 1995; DiIorio, Faherty et al., 1992; DiIorio Hennessey, et al., 1996; DiIorio, Shafer, Letz, Henry, Schomer et al., 2004 DiIorio, Shafer, Letz, Henry, Schomer and Yeager, 2006; DiIorio, Reisinger et al., 2009). The results obtained from administering the Epilepsy Self-Management Scale (ESMS) survey (Appendix A) assisted caregivers and patients in identifying and understanding the issues that play a role in determining patients’ knowledge, increasing their self-management skills, and modifying their behaviors when dealing with epilepsy.

The ESMS is a 38-item scale that measures the frequency with which epilepsy patients engage in self-management behaviors. Each behavior is rated on a five-point scale from 1 (“Never”) to 5 (“Always”). The ESMS is a valid and reliable instrument (DiIorio, Shafer, Letz, Henry, Schomer et al., 2004). The original ESMS survey consisted of 26 items that were categorized into three areas: (a) medication-related issues, (b) safety-related issues, and (c)
general lifestyle management issues. A total possible score ranges from 38 to 190. The original survey was evaluated by a panel of epilepsy management experts to assess content validity. Content validity assessment identified a validity index of 93%, indicating that the reviewers strongly agreed that the items included in the survey measured self-management behaviors (DiLorio, Hennessy et al., 1996). The internal consistency for this survey ranged from 0.81 to 0.86. (DiLorio and Henry, 1995).

Following a review of the original 26-item instrument, DiLorio, along with other expert researchers, added 12 items to the ESMS to address lifestyle and safety issues. The new items were developed after conducting a comprehensive literature review on epilepsy self-management and discussing this issue with epilepsy patients and health professionals caring for epilepsy patients. This survey focuses on five areas: medication, information, safety, seizures, and lifestyle management (DiLorio, Shafer, Letz, Schomer, & Yeager, 2004). Each item expresses a behavior or condition and asks the responder to rate the extent to which he or she agrees with the statement. An example of an item within the lifestyle subscale is “I do such things as relaxation, guided imagery, and self-hypnosis to manage stress.” An example of an item with the medication subscale is “When my seizure medication is running out, I spread out the time between doses.” Obtaining a high score correlates with more frequent use of epilepsy self-management strategies. The survey was written at the sixth grade level as determined by the Flesch Reading Ease (FRE) scale. The author of this paper contacted the author of the ESMS, Colleen DiLorio, Ph.D., via electronic mail to discuss this evidence-based project and subsequently obtained permission to use the survey. A clinic neurologist assisted the project leader in identifying the most appropriate sample and type of intervention for this project based on the evidence..
**Persuasion**

The second phase is the persuasion phase. During the persuasion phase, a critical assessment of the characteristics of an innovation, organization, individual influences, environment, and decisions to adopt or reject the innovation occurs (Lovejoy, Demireva, Grayson & McNamara, 2009). According to Rogers (1995, 2003), innovation practice change is a dynamic process in which ideas spread via communication channels between and among members of an organization over time. Characteristics of the innovation, the organization, the environment and the individuals involved exert a substantial influence over whether an innovation is adopted or not adopted by the stakeholders (DiCenso et al., 2005). The strategies and rationale used in the persuasion stage of this project were academic detailing and educational outreach. Academic detailing and educational outreach were used to meet and discuss the purpose of the epilepsy self management protocol with the nurses, physicians and clinic staff. The author met with the nurses and the neurologist to discuss implementing an epilepsy self management protocol in an outpatient clinic. This phase provided opportunities to share information about the need for educating epilepsy patients about living with epilepsy.

**Decision**

The third phase was the decision phase. During the decision phase, the influence of stakeholders who support the decision to put a new innovation into practice is essential. The stakeholders in this project were the neurologist, registered nurses and the author of this paper. During the decision-making process, stakeholders in the outpatient neurology clinic supported the implementation of an epilepsy self-management protocol because epilepsy patients typically support and value education provided by nurses. Having the opportunity to speak at length with healthcare providers increases the knowledge of epilepsy patients and their ability to care for
themselves. (Barkley, 2003; Bradley & Lindsay, 2009; Mills et al., 2002; Risdale et al., 1999, 2002).

**Implementation**

The fourth phase is the implementation phase. The implementation phase is characterized by the stakeholders or organization adopting a new innovation and devising strategies to incorporate it into everyday clinical practice (DiCenso et al., 2005). This phase occurred when the self management protocol was integrated into the clinical practice. Educating patients and encouraging them to integrate healthy lifestyle management skills and behaviors promotes health improvement and better quality-of-life decisions. Healthcare providers want their patients to become more independent in providing self-managed care and thus improve their overall health.

**Confirmation**

The final phase is the confirmation phase. Following the implementation of any new practice innovation, practitioners should evaluate the impact of the change in practice and the implementation process during a confirmation phase. The confirmation phase allowed stakeholders to review and evaluate the implementation of the new practice innovation. This evaluation process provided information and analysis that helped practitioners decide whether to incorporate the new innovation into the practice setting (DiCenso et al., 2005).

**Health Promotion Model**

Pender's (2002) health promotion model (HPM) guided the development of the patient education component of the project. The HPM was developed to explain health-promoting behaviors (such as exercising regularly) and health-protecting behaviors (such as complying with daily seizure medication protocols) (Ronis, Hong & Lusk, 2006). The HPM is based on
expectancy-value theory (EVT) and social cognitive theory. Bandura's (1997) social cognitive theory has been used as a theoretical framework by researchers cited in the scholarly research literature on epilepsy self-management (Ronis, Hong, & Lusk). A foundational principle in social cognitive theory is that individuals with high self-efficacy, i.e., confidence in their abilities--are more likely to meet goals and overcome challenges (DiLorio, Shafer, Letz, Schomer, & Yeager, 2006.) Pender (2002) identified two categories of predictors of health-related behaviors: (a) individual characteristics and experience, and (b) behavior-specific characteristics (Ronis, Hong, & Lusk). People’s individual characteristics and experience influence their behavior-specific characteristics.

The HPM provides a suitable theoretical framework for this project because educating epilepsy patients about their disease will increase their knowledge about epilepsy and self-management options. Increasing epilepsy patients’ understanding of self-managed care empowers them to improve their self-management abilities related to healthcare, which likely will have a positive effect on their health status. When epilepsy patients discover that improved self-managed care results in a healthier and potentially seizure-free lifestyle, they likely will continue to monitor and adjust their self-managed behaviors.

People are more likely to change a behavior if they perceive a threat to their health status, especially if they believe the benefit of taking action to improve their health status outweighs the perceived barriers they may encounter as they attempt to engage in health-promoting behaviors (Pender, Murdaugh, & Parsons, 2011). In the present evidence-based project, the HPM framework was adapted (Figure 1) to evaluate the influence of an epilepsy self-management protocol on the health behaviors of a small group of epilepsy patients.
Figure 1
Cole adaptation of the Health Promotion Model for Management of Epilepsy

According to Pender, Murdaugh, and Parsons (2011), specific personal factors and prior related behaviors directly and indirectly affect any action. In the HPM, personal factors are categorized as biological, psychological, and sociocultural. Personal factors of participants in this study included the following: diagnosis of epilepsy, inability to work or drive due to seizures, difficulties associated with being perceived as different from others, difficulty remaining in compliance with medication protocols, and financial assistance required to obtain medication.

Some prior related behaviors included driving when seizures were not controlled, failure to take anti-epileptic medications as prescribed, and engaging in unsafe behaviors—e.g., operating heavy machinery or working at heights. As healthcare providers, nurses offer a natural avenue to help patients understand personal and prior related factors that influence their ability to self-manage their disease. When nurses are able to help patients identify the benefits of positive behaviors, they are better positioned to help them overcome any barriers that might inhibit them from engaging in these positive behaviors (Pender, Murdaugh, & Parsons, 2011; Srof & Velsor-Friedrich, 2006). These behavior-specific variables within the HPM are important in promoting self-managed care because they can be modified through intervention. (Ronis, Hong & Lusk, 2006). These variables represent measurable factors that play an important role in assessing whether an intervention has facilitated a change in behavior (Pender, Murdaugh, & Parsons, 2011). These variables include perceived benefits, perceived barriers, perceived self-efficacy, activity-related affect, interpersonal influences, and situational influences.

Perceived benefits of engaging in self-managed healthcare behaviors include the positive outcomes that result from these behaviors, and increasing one’s knowledge about epilepsy may lead to more effective seizure management; decreased seizure frequency; and the opportunity to drive, work, and play (Pender, Murdaugh, & Parsons, 2011). Perceived barriers have the
opposite effect on behavior. That is, if people do not believe that the benefits of taking action to improve their health status outweigh the perceived barriers, they are less likely to make a commitment to engage in health-promoting behaviors. (Ronis, Hong & Lusk, 2006).

According to research (DiIorio, Faherty et al., 1992; DiIorio and Henry, 1995), epilepsy patients are less committed to the process of improving the management of their disease because of insufficient knowledge, insufficient monetary funds, lack of educational resources, poorly controlled seizures, and insufficient social support. When facing such obstacles, it becomes easy to understand how patients become discouraged and unmotivated to change their behaviors. However, emphasizing the aspects of their behavior that they can control provides epilepsy patients with a starting point for changing their behavior and provides a foundation to support future and ongoing positive behaviors (Srof & Velsor-Friedrich, 2006).

Bandura (1997) has defined “self-efficacy” as a belief in one’s personal capability to accomplish specific tasks, overcome obstacles, and achieve goals. Self-efficacy is influenced by activity-related affects, and the more positive the activity-related affect, the greater the self-efficacy. Therefore if engaging in a particular behavior results in positive feelings, people are more likely to continue that behavior (whatever it may be) and, as a natural consequence, become more proficient at it. In other words, the higher the self-efficacy, the lower or less difficult the perceived barriers become (Pender, Murdaugh, & Parsons, 2011).

Logically, then, the opportunity to practice health-promoting epilepsy self-management behaviors can potentially increase self-confidence and improve patients’ ability to manage epilepsy, thereby decreasing perceived barriers, such as insufficient knowledge, financial deficits, and noncompliance with medication protocols (Ronis, Hong & Lusk, 2006).

Interpersonal influences include perceptions of the behaviors, ideas, and opinions of relatives,
friends, and health care providers (Pender, Murdaugh, & Parsons, 2011). According to Pender, Murdaugh, and Parsons (2011), three interpersonal influences determine whether an individual will adopt health-promoting behaviors: (a) social support, (b) expectations of others, and (c) meaningful observations of others engaging in specific behaviors. As healthcare providers, one key component of our work is to support our patients by encouraging, educating, and empowering them as they struggle to overcome the challenges of living with epilepsy. The more we motivate our patients to confidently self-manage their epilepsy, the more likely they will commit to engaging in health-promoting behaviors. Situational influences may directly impact behavior by creating environments that feature prompts to encourage positive action (Pender, Murdaugh, & Parsons, 2011).

Patients are more likely to perform adroitly in a supportive, reassuring, and safe environment than one that is under supported, unsupported, or hostile. Educating patients in a non-judgemental fashion is a situational influence that allows them the opportunity to feel safe and encourages them to identify and maintain positive self-management behaviors. When nurses identify strategies that facilitate and reinforce positive self-management behaviors in a safe environment, patients are more likely to commit to a plan of action that includes positive self-managed behaviors (Pender, Murdaugh, & Parsons, 2011).

Immediate and competing demands and preferences can impede the planned commitment to health-promoting behaviors before implementation occurs. Patients have very little, or at the most, a low level of control over competing demands, such as demanding or rigorous work schedules, family obligations and requirements, and other personal choices or lifestyle preferences. Choosing to neglect a competing demand may have deleterious effects both on patients as well as their significant others (Pender, Murdaugh, & Parsons, 2011). An example of
a competing preference is choosing to take a bath instead of a shower even though the likelihood of drowning during a seizure is greater while taking a bath than while taking a shower. Another example of a competing demand is choosing to follow the driving restrictions due to poor seizure control--a decision which, while safe, also may prevent a parent from driving children to and from school. Both competing preferences and competing demands can potentially interfere with the ability to meet commitments to a plan of action and ultimately to attain positive health outcomes (Pender, Murdaugh, & Parsons, 2011). Epilepsy patients who choose to integrate positive self-management behaviors may enhance their overall health, increase their understanding of their disease, and improve their quality of life.

Summary

Being diagnosed with epilepsy can have far-reaching physical and psychosocial effects that are just as or more difficult to deal with than having a seizure (Couldridge, Kendall, & March 2001; MacDonald, Torrance, Wood, & Womersley, 2000). Having increased knowledge about epilepsy and improving self-management behaviors are important factors in improving one’s ability to effectively cope with epilepsy and to minimize its impact on physical and psychosocial functioning (Doughty, Baker, Jacoby, & Lavaud, 2003). The Living Well with Epilepsy Conference (Barkley, 2003) reported that self-management needs to be an area of focus, but due to lack of accessibility, lack of availability, and lack of insurance coverage, many patients with epilepsy do not have access to educational and support programs. Pender's health promotion model (HPM) (Pender, Murdaugh & Parsons, 2011) and Rogers’ (1995, 2003) diffusion of innovations theory provide the theoretical frameworks in guiding the implementation and evaluation of this evidence based project.
Evidence

Literature Review and Synthesis

The first literature search was conducted in June of 2010 using the following search terms: *epilepsy*, *social support*, and *self-efficacy*. The search was conducted using sources from the following research databases: Cochrane, PUBMED, CINAHL, and PSYCHINFO. Articles selected for inclusion in this literature review were published between the years 1999 and 2011. There were also three sentinel articles from 1992, 1995 and 1996 that are also included in this paper. These three articles were written by Dr DiIorio and specifically address the self-management theory and survey scale. Using the same databases, six separate literature reviews were conducted between June 2010 and June of 2011 using following terms: *epilepsy*, *self-management*, *social support* and *self-efficacy*.

More than 120 research articles were initially reviewed for this project, and 26 were eventually selected for inclusion in this literature review. The quality of the 26 research articles included in this literature review was determined using a method of ranking based on the work of Ackley, Swan, Ladwig and Tucker (2008), which identifies seven levels of evidence based on the strength of the study. The articles for this study ranged in quality from Level II to Level VII. Because few randomized controlled trials (RCT) have been conducted in the self-management research arena, most articles reviewed for this study consisted primarily of descriptive survey studies. However, this literature review does include two important research synthesis articles. One article was by Bradley and Lindsay (2009) and a second synthesis article was by Coster and Norman (2009). Bradley and Lindsay identified thirteen RCTs, 16 reports, and seven papers that reported on five trials involving nurses specializing in epilepsy patient care. This literature review identifies some moderately robust research evidence to support the effectiveness and low-
cost benefit of utilizing specialized epilepsy nurses and self-management programs for people with epilepsy (Barkley, 2003; DiLorio, Faherty et al., 1992; DiLorio Hennessey, et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer et al., 2004; DiLorio, Shafer, Letz, Henry, Schomer and Yeager, 2006; Elliott & Shneker, 2008; Kendall Thompson, Couldridge, 2004; McAuley, McFadden, Elliott, & Shneker, 2008; Pramuka, Hendrickson, Zinski, & Van Cott, 2007; Risdale, Morgan, & O’Connor, 1999; Risdale, Kwan & Morgan, 2002; Unger & Buelow, 2009). Coster and Norman conducted a review of 30 journal articles on educational and self-management interventions in order to identify best practices and guide nurses who care for patients with chronic illnesses, such as epilepsy, diabetes, cardiovascular disease, and chronic obstructive pulmonary disease. The authors identified several known issues regarding educational and self-management interventions. They confirmed that nurses are the most likely group of health care providers to conduct patient education. Increasing the awareness and capabilities of patients to manage their diseases is becoming an increasingly widespread practice in the health care community. Unfortunately, there is a paucity of research data on the benefits of educating patients about disease management and the effectiveness of nursing interventions for patients with chronic illnesses (Coster & Norman 2009). Coster and Norman reviewed seven articles. The research question that Coster and Norman (2009) addressed was “What impact do specialised interventions for epilepsy have on seizure frequency, quality of life, and health status for adults with epilepsy?” (p. 516). The types of interventions performed in the research studies included self-management group education, guidelines plus education, self-monitoring medication side effects, and informational pamphlets compared to standard care. These researchers discovered that seizure frequency and medication management were improved by self-management protocols. Identifying medication side effects did reduce the number of adverse
events and clinic visits, but giving pamphlets to patients with or without education was not beneficial.

Rajpura and Sethi (2004) reviewed ten years of epilepsy research regarding the educational and counseling needs of people with epilepsy. After reviewing 15 papers, they concluded that people with epilepsy want educational information on epilepsy in general, driving, lifestyle management, employment, seizure types, medication, side effects from medication, treatment options, and seizure control. Anxiety, depression and emotional support were the counseling needs identified by people with epilepsy. May and Pfafflin (2002) evaluated the efficacy of one epilepsy educational program MOSES (Modular Service Package Epilepsy). The program was developed to assist epilepsy patients by educating them about their disease and to improve their coping with epilepsy by encouraging self management so patients become experts in living with their disease (May & Pfafflin, 2002). MOSES is a fourteen module program developed in Germany. The modules cover such topics as living with epilepsy, epidemiology of epilepsy and psychosocial aspects of epilepsy. Each module is 60 minutes in length. Using a pretest and post-test study design, the researchers examined the experiences of 129 patients who completed the educational program compared to 113 patients who did not. Results of the study revealed that patients who participated in the MOSES program had improvements in epilepsy knowledge and ability to cope with epilepsy. May and Pfafflin (2002) findings supported previous research findings (Barkley, Buelow, & Johnson, 2000; Cochrane, 1995; Dilorio et al.; Rajpura and Sethi, 2004; Coster & Norman, 2009) that epilepsy patients need educational intervention regardless of the duration of their disease. Communication with others about epilepsy and its psychosocial aspects improved in patients who participated in the MOSES educational program (May & Pfafflin, 2002). The researchers identified the fact that the MOSES
program encouraged interaction between participants and encouraged them to discuss their feelings and concerns.

In 11 studies, epilepsy nurse specialists were found to assist the general communication process between the patient and healthcare providers while meeting the educational needs of patients (Rajpura and Sethi, 2004). The review and synthesis of several research articles revealed that epilepsy patients have important educational needs that are not being met (Barkley, 2003; Buelow & Johnson, 2000; Cochrane, 1995; DiLorio and Henry, 1995; DiLorio, Henessey, et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer & Yeager 2004; DiLorio, Shafer, Letz, Henry, Schomer & Yeager 2006; Elliott & Shneker, 2008; Kendall et al, 2004; McAuley et al., 2008; Pramuka et al., 2007; Rajpura & Sethi, 2004; Risdale et al. 1999, 2002; Unger & Buelow, 2009). Robinson, Edwards, Madigan, Ledger, and Boutros (2000) surveyed patients in an outpatient epilepsy clinic. They found most patients knew more general information about epilepsy than their own health condition. Health care providers need to understand and evaluate the knowledge base of their patients and then share that information with patients.

Unger and Buelow (2009), using a qualitative research design studied newly diagnosed epilepsy patients to analyze and define the concept of self-management. They identified three framework domains when caring for and educating epilepsy patients: (a) lifestyle management, (b) seizure management, and (c) medication management (Unger & Buelow). Some examples of lifestyle management include maintaining adequate exercise habits and practicing good sleep hygiene in order to maintain good health. Seizure management includes notifying health care providers after experiencing a seizure, and medication management includes maintaining compliance and taking the anti-epileptic medications as prescribed.
The review of literature pertaining to this topic revealed five important components relevant to the content and implementation of this project: (a) “self-management” is a continually changing construct that is dependent on patients’ perceptions of their health status; (b) the Epilepsy Self Management Scale (ESMS) is the only tool presently available to measure the frequency with which people with epilepsy implement strategies to manage epilepsy; (c) epilepsy patients need more educational information about their disease and how they can best manage it to improve health outcomes and quality of life; (d) patients perceive epilepsy nurses to be well equipped to educate them about their disease; and (e) receiving both written and oral educational information is the more efficacious than receiving either one individually. In order to effectively care for epilepsy patients, it is imperative that healthcare providers gain a better understanding of the motivating factors that encourage patients to engage in certain self-management behaviors (Rajpura & Sethi, 2004; Unger & Buelow, 2009).

**Recommendation for Practice Plan Change**

After conducting a literature review on the topic of epilepsy and self-management, the project leader concerns were discussed with the collaborating neurologist. The proposed practice change focused on five educational recommendations based on the knowledge and research deficits identified in the literature. Epilepsy patients need and want more knowledge about epilepsy in general as well as their condition specifically. Epilepsy nurse specialists are cost effective, improve patients knowledge and satisfaction but further research needs to be done to show health outcomes in patients with epilepsy (Rajpura & Sethi, 2004). The recommendations are clearly effective and supported by rationale gleaned from the literature (Barkley, 2003; Buelow & Johnson, 2000; Cochrane, 1995; Dilorio and Henry, 1995; Dilorio, Henessey, et al., 1996; Dilorio, Shafer, Letz, Henry, Schomer & Yeager 2004; Dilorio, Shafer, Letz, Henry,
The proposed practice change is the implementation of an epilepsy self-management protocol to improve the quality of life and health outcomes of people with epilepsy. The proposed recommendations for the development and implementation of an epilepsy self-management protocol are as follows:

**Recommendation I:** Healthcare providers need to give epilepsy patients accurate, current educational information about their disease. This will increase patient knowledge, improve their self efficacy to care for themselves and possibly reduce patient mortality rates.(DiLorio, Hennessey, et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer, and Yeager 2004; Couldridge et al., 2001; Unger & Buelow, 2009)

**Recommendation II:** Health care providers need to give patients with epilepsy both written and verbal educational information about medication, driving, safety, types of seizures and lifestyle management. Patients are less confident in their knowledge about medication side effects, healthy lifestyle behaviors, medication adherence, and seizure. This increased knowledge about epilepsy correlates with better coping, and improved self esteem. Epilepsy patients will be better educated and feel more confident dealing with their disease on a daily basis. Patients will perceive the teaching to be improved quality care. (Couldridge et al., 2001; DiLorio and Henry, 1995, DiLorio, Shafer, Letz, Henry, Schomer, and Yeager 2006; Kendal et al., 2004; Pryse-Phillips et al., 1982)

**Recommendation III:** Self management education needs to be provided by nurses with expertise in epilepsy. Nurses are effective as epilepsy patient educators. Patients perceive nurses
as having improved levels of communication. Patients were more satisfied with nurse advice and identified nurses as being just as knowledgeable about epilepsy as physicians, but nurses have more availability to sit and share knowledge and answer questions. Patients with low self-efficacy would benefit from nursing interventions that increase their self-efficacy, thereby improving their ability to self-manage their disease and quality of life. With increased self-efficacy, patients will feel more confident to ask questions and will be able to decrease their knowledge deficits (Risdale et al., 1999, 2002, 2004; Bradley & Lindsay, 2009).

Recommendation IV: Health care providers need to educate the general public, other providers, and family members about epilepsy in order for them to have a better understanding of epilepsy and be less fearful and anxious about being around people with epilepsy. Better education of the public, providers, and family members will improve the quality of life for seizure patients and lead to decreased feelings of stigma (DiLorio, Shafer, Letz, Henry, Schomer and Yeager, 2006; Barkley 2003; Bradley & Lindsay, 2009)

Recommendation V: Health care providers need to put more effort into developing self-management protocols for people with epilepsy. Patients will have better health outcomes and an improved quality of life if they do this (Bradley & Lindsay, 2009; Barkley 2003; McAuley et al., 2008).

Assessing Organizational Readiness for Change

Readiness for change is a key component of any new protocol or practice change innovation that affects stakeholders and ultimately the outcome of the project. The epilepsy patient care team, the individuals who will implement the epilepsy self-management protocol, and the patients are the primary stakeholders of this project. According to Rogers (2003), the speed of innovation diffusion increases when support for the innovation is obtained from
stakeholders and early adopters (Lovejoy et al., 2009). The practice change innovation was discussed with the neurologist, and his support was obtained very early in the process of preparing for this project. The project leader, who is a core member of the team, has always been an advocate of patient care and patient education. The project leader was an early adopter and supporter of this planned project.

Additional readiness for change has been demonstrated by frequent requests for additional patient contact. Specifically, the registered nurse at the triage desk in the patient triage phone room has requested that nurses provide additional patient contact. Because patients enrolled in this project were new to the clinic, they were unaware that a change in protocol has taken place. In response, formative feedback from patients and stakeholders will be requested regarding the content and quality of the implementation process. This formative feedback was obtained verbally from the stakeholders during weekly clinic meetings, via email, and on an as-needed basis. Previous research findings have indicated that epilepsy self-management consists of a variety of behaviors and actions that patients use to manage their seizures, medications, safety, and lifestyle issues (Barkley, 2003; Buelow & Johnson, 2000; Cochrane, 1995; DiLorio and Henry, 1995; DiLorio, Hennessey, et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer, and Yeager 2004, 2006; Elliott & Shneker, 2008; Kendall et al., 2004; McAuley et al., 2008; Pramuka et al., 2007; Risdale et al., 1999, 2002). In order to care for epilepsy patients effectively, healthcare providers must possess a better understanding of what factors motivate patients to engage in specific self-management behaviors (Unger & Buelow, 2009). Implementing this self-management protocol will assist the epilepsy team/stakeholders in understanding patients’ perspectives and will guide the team members in their efforts to improve patient health outcomes and quality of life.
Clinical Feasibility and Usefulness

Bradley and Lindsay (2009) provided moderately convincing evidence to support the effectiveness and low-cost benefit of utilizing specialized epilepsy nurses and self-management programs when treating epilepsy patients. This evidence has been supported by other researchers (Barkley, 2003; DiLorio and Henry, 1995; DiLorio, Hennessey et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer and Yeager, 2004; Elliott & Shneker, 2008; Kendall et al., 2004; McAuley et al., 2008; Pramuka et al., 2007; Risdale et al., 1999, 2002; Unger & Buelow, 2009). Currently, the standard practice in the outpatient neurology clinic is to present new patients with an educational folder containing pamphlets and articles that provide information about a variety of epilepsy-related topics.

Current practice does not include reviewing this information with patients, nor is the selection of information provided to patients based on its applicability to their current knowledge level or disease management attitudes and behaviors. Similarly, during new-patient appointments, patients do not meet with nursing staff regarding their educational needs and no educational information is provided at that time. Several researchers found that people generally believed that it would be most beneficial to see a nurse when they were first diagnosed with epilepsy. It is evident from literature that improving patients' knowledge about their epilepsy will positively influence their self-efficacy and management of their disease, thereby improving their symptoms and diagnosis (Risdale et al., 1999, 2002; Kendal et al., 2004; Bradley & Lindsay, 2009). Because of this lack of information, it is likely that implementing an epilepsy self-management protocol will increase patient visit time and will enable healthcare providers to better serve the epilepsy patient population. The protocol is also likely to increase knowledge and understanding about patient concerns and knowledge deficits so that healthcare providers
can increase their capability of managing their disease. The protocol includes a step-by-step process to help practitioners evaluate and educate epilepsy patients. The protocol is feasible because it will be accessible to the RN, NP, and other healthcare team members who work in the neurology clinic. The protocol was located in a commonly used cabinet along with other epilepsy educational materials and is located in the clinic. All of the patient educational packets and the ESMS will be stored in the cabinet and easily accessed by all practitioners. The primary neurologist has expressed support for the implementation of this protocol.

**Epilepsy Self Management Protocol**

The epilepsy self management protocol (Table 1) was developed by the author to be used in an outpatient clinic setting. The protocol provides a detailed step by step process and rationale for the implementation. The steps of the protocol are “evaluate,” “educate,” “follow up,” and “documentation of outcome.” The first step of the protocol is to evaluate patients’ current self management behaviors and knowledge base. One way of accomplishing this determination is to administer the Epilepsy Self Management Scale (ESMS).

The second step of the protocol is to educate patients about epilepsy and positive self management behaviors. During the appointment, epilepsy patients will engage in an educational session with a nurse or NP after completing the Epilepsy Self Management Scale (ESMS). The patient will receive an educational sheet (Appendix B) that provides information about lifestyle, medication, and seizure-management issues; two pamphlets from the Epilepsy Foundation, Types of Seizures” and "Medicines for Epilepsy," a seizure diary and a bookmark containing information about how to administer first aid to someone experiencing a seizure.

The third step of the protocol is follow up. Patients will receive a follow-up phone call one to two weeks after their first appointment. A follow-up phone call will be made one to two
Table 1
Implementation of Epilepsy Self Management Protocol

<table>
<thead>
<tr>
<th>Steps</th>
<th>Purpose</th>
<th>Activity</th>
<th>Source</th>
<th>Level of Evidence</th>
</tr>
</thead>
</table>
| Educate          | Increase patients’ knowledge about epilepsy and lifestyle management to decrease seizure frequency and increase self efficacy | 1. Review patients’ survey responses  
2. Answer any questions patient and family may have in clinic today  
3. Give and review with patient the educational sheet  
4. Give patient appropriate pamphlets on medication, safety and types of seizures and seizure diary  
5. Inform patient a follow up phone call will occur in 1-2 weeks to answer any questions or concerns | Pryse-Phillips et al., (1982)  
Bradley & Lindsay, (2009)                             | II                |
| Follow up        | Ensure all patient questions and concerns were addressed and identify any lingering issues that need attention | Call patient at home 1-2 weeks after first clinic appointment                                                      | Kobau & DiLorio (2003)                       | III               |
| Documentation of outcome | Measure effectiveness of educational intervention and change in level of patient awareness | Patient completes Epilepsy Self Management Survey at second clinic appointment. Score on second survey is compared to score on survey completed at first clinic visit | Risdale, Morgan & O’Connor (1999)           | III               |
The third step of the protocol is follow up. Patients will receive a follow-up phone call one to two weeks after their first appointment. A follow-up phone call will be made one to two weeks after the first appointment to inquire whether the patient has any additional questions subsequent to reviewing the information or has experienced any problematic issues.

The fourth step of the protocol documenting outcomes, will occur when the new patients return four to six weeks later for their follow up appointments. The last step is important because it allows the health care providers the opportunity to measure effectiveness of the intervention. Patients will be asked to complete the ESMS a second time so that scores from their first survey (pre-intervention) can be compared with scores from their second survey (post-intervention). Finally, any changes in their scores between the first and second administrations can be identified and the results interpreted.

**Project Implementation**

**Setting**

A midwest academic outpatient clinic was selected as the practice setting for this evidence-based project. This setting was chosen because it represents a setting similar to those identified in the epilepsy-related literature base. Previous researchers, Kobau and Dilorio, 2003; Dilorio, Shafer, Letz, Henry, Schomer and Yeager,2006; Dilorio, Reisinger et al.,2009, utilized participants who were patients receiving epilepsy care in academic clinic settings. Selection of the project criteria and study population were based on the review of research studies cited for this project and the assistance from the primary neurologist at the clinic. The majority of the literature consisted of descriptive survey studies involving epilepsy patients enrolled in an outpatient clinic setting.
Ethical/Legal Implications

Approval from the University of Toledo institutional review board (IRB) was obtained prior to implementing the protocol. The implementation of this project involved minimal risk to the population of interest. There are legal implications associated with the diagnosis and the management of epilepsy. Having seizures affects all aspects of life. Driving is an important issue for everyone especially individuals with epilepsy. Individuals with seizures that impair consciousness may be endangering themselves and society when operating a motorized vehicle (Drazkowski, Neiman, Sirven, McAbee and Noe, 2010). The medications taken to treat seizures can cause side effects such as drowsiness or impaired thinking. Each state has its own rules and requirements regarding driving and seizures. Depending on the state, a person with seizures is required to be seizure free for six to eighteen months prior to operating a car. Some states require the healthcare provider notify the state license bureau if a patient has seizures (Drazkowski et al., 2010). Unfortunately, not all states offer immunity from disciplinary action to the healthcare provider for violating patient confidentiality after reporting a patient (Drazkowski et al., 2010). Elliott and Long (2008) surveyed 213 patients with epilepsy about their driving and if they disclosed this information truthfully to their healthcare providers. The researchers (Elliott & Long, 2008) found that 26% disclosed information about a seizure related motor vehicle crash, but almost 20% were not truthful when asked about their seizure frequency. Drazkowski et al., 2010 surveyed 159 patients with epilepsy about their prior experience with counseling for driving in a state that has mandatory reporting(62) versus patients with epilepsy in a state without mandatory reporting (97). The researchers found that less than 50% of the patients were counseled about driving by their healthcare provider. In fact there was less counseling performed
by healthcare providers in the mandatory reporting state than in the state with voluntary reporting (Drawotzky et al., 2010). Healthcare providers need to improve their patient counseling in regards to patients with epilepsy and driving. Implementing an epilepsy self management protocol will improve the performance gap that exists in the counseling on driving.

**Population of Interest**

The population of interest was new epilepsy patients who received treatment in the neurology outpatient clinic. The rationale for choosing new patients is that previously all new patients received an educational packet, so for this evidence-based project, our change in practice was to continue giving the new patients an educational packet with the addition of an educational session with a nurse. The population of interest appropriate for this protocol includes the following demographic characteristics:

1. Patients diagnosed with epilepsy who are currently receiving treatment for seizures.
2. Age 18 years and older
3. Able to read and understand English.
4. Mentally competent as evaluated by a healthcare provider.
5. Willing to participate.

**Exclusion criteria:**

1. Patients not diagnosed with epilepsy.
2. Age younger than 18 years
3. Unable to read and understand English.
4. Developmentally delayed and/or mentally incompetent as evaluated by a healthcare provider
5. Unwilling to participate.
The ages of participants ranged from 20 years to 65 years; 55% were male, and 45% were female. The median age was 35 years. Years diagnosed with epilepsy ranged from less than one year to 50 years. For the majority (65%) of participants, the total household income was less than $20,000. Ethnic backgrounds were varied, including Caucasian (65%, n=13) African American (10%, n=2), Hispanic (10%, n=2), Asian (5%, n=1) American Indian (5%, n=1), and other (5%, n=1). Fifty percent of the participants were high-school educated and had received either a GED certificate or diploma. Twenty percent had completed two years of trade school or college. The remaining 30% had not graduated from high school (10%, n=2) obtained a four-year college degree (10%, n=2) or completed post graduate studies (10%, n=2). Regarding employment status, 65% were unemployed. Of the 65% who were unemployed, 40% were receiving disability. Twenty percent were working full time, and 15% were working part time. Sixty percent rated their seizures as not controlled. When asked what activities were affected because of their seizures, 50% identified not being able to drive.

The benefits of implementing the epilepsy self management protocol, for patients included increased knowledge about their disease as well as increased self-efficacy in performing self-management behaviors. As a result, they are likely to experience improved health outcomes and higher quality of life (Bradley & Lindsay, 1995; Dilorio, Hennessey et al., 1996, Dilorio, Shafer, Letz, Henry, Schomer and Yeager, 2004, 2006; Dilorio, Reisinger et al., 2009).
Cost Analysis and Resources

Table 2
Total cost per patient for Epilepsy Self Management Protocol

<table>
<thead>
<tr>
<th>Staff Cost</th>
<th>Supply Cost per patient</th>
<th>Paper and Copying Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>RN $26 per hour</td>
<td>Pocket Folders $0.85</td>
<td>White paper = $.06 per page</td>
</tr>
<tr>
<td></td>
<td>“Type of Seizure” pamphlet $1.25</td>
<td>Copy charge $.0625 per page</td>
</tr>
<tr>
<td></td>
<td>“Medicines for Epilepsy” pamphlet $2.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Seizure diary $0.10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Safety bookmark =$0</td>
<td></td>
</tr>
<tr>
<td>Total nurse cost per patient= $13.00-$26.00</td>
<td>Total supply cost per patient= $4.20</td>
<td>Total paper cost= $0.06 Copy cost= $1.25</td>
</tr>
</tbody>
</table>

The Department of Neurology has earmarked funds to be used for educational purposes, and for this project. The cost for the folders and pamphlets as well as paper and copying will be paid for by the department. The educational packet preparation was completed by the project leader during regularly scheduled work hours, so no additional expenses will be incurred for her work time. The number of packets prepared was based on the number of new patients scheduled in clinic. The time that nurses spent with each new patient was 30-45 minutes depending on the number of questions and concerns the patient and /or family had. The nurse or NP conducted the educational session during normal work hours, so no additional expenses will be incurred. The neurologist would page the nurse only if a new patient was a potential candidate for the project, otherwise the nurse continued completing her own daily tasks. The identified costs for implementing this project are identified in Table 2.
The resources required to implement this project include the team members, patients, the Epilepsy Foundation and "Talk About It" web sites. A registered nurse assisted the nurse practitioner in conducting the patient educational sessions. The neurologist was available to provide consultation and feedback regarding the educational sessions and materials. The patients participated in the educational sessions. The pamphlets were obtained from the Epilepsy Foundation of America (EFA) website. The patients were encouraged to visit the EFA and "Talk About It" web sites for information and support for their epilepsy.

**Evaluating Outcomes**

DiLorio and Henry, 1995; DiLorio, Hennessey et al., 1996; DiLorio, Shafer, Letz, Henry, Schomer and Yeager, 2004) identified evidence confirming a positive correlation between self-efficacy and self-management in patients with epilepsy. Kobau and DiLorio (2003) found that epilepsy patients have more self-efficacy for healthy medication management behaviors than for healthy lifestyle management behaviors. Pender’s (2002) health promotion theory provides an appropriate theoretical framework that accurately reflects the purpose of this project because research has indicated that educating epilepsy patients about the disease increases their knowledge about epilepsy and how to best manage it.

Increasing the knowledge of individuals with epilepsy empowers them to provide improved self-care which positively affects their health status. When epilepsy patients discover that living healthier and possibly seizure free is the result of improved self-management, they will be more likely to continue these behaviors.

Patients with increased knowledge about their disease feel more capable of performing self-management behaviors as well as experience improved health outcomes and a higher quality of life (Cochrane, 1995; DiLorio and Henry, 1995; DiLorio, Hennessey et al., 1996; DiLorio,
Shafer, Letz, Henry, Schomer and Yeager, 2004; DiLorio, Reisinger et al., 2009). The outcome measures and evaluations planned for this project appraised both the implementation process and the content of the implementation. Rogers’ (1995, 2003) diffusion of innovation theory was used to guide the protocol implementation process.

The final stage of Rogers’ theory (1995, 2002) is confirmation, which is related to the knowledge stage in that it provides a method for evaluating the effectiveness of the implementation process. The method of outcome measurement will be performance-related and patient-related outcomes. Evaluation forms (Appendices C & D) completed by the practitioners and patients will serve as an evaluation instrument to record the performance-related outcomes. High-quality evidence-based literature provides support for the chosen outcome measures.

Patient-related outcomes were measured using a validated survey completed by the patient before and after the educational intervention. The Epilepsy Self-Management Scale (ESMS) will assist caregivers and patients in identifying and understanding the issues that play a role in increasing patients’ knowledge, improving their self-management skills, and changing unwanted behaviors associated with dealing with their epilepsy. The ESMS is a valid and reliable survey, and permission to use the survey was obtained from its author.

A primary desirable outcome of the project is an increased score on the second administration of the ESMS compared to the ESMS survey completed during the first appointment, which would correlate with an increased understanding of epilepsy and the ability to manage it. The secondary outcomes include increased understanding among epilepsy patients about their medication and lifestyle issues, such as driving and safety, as well as improved patient satisfaction based on increased opportunities to discuss their concerns. During educational sessions, patients will be asked to explain in their own words their understanding of
the information provided to them as a method of verifying comprehension. The project leader was responsible for confirming that all evaluations and surveys are completed.

**Project Evaluation**

**Implementation Process**

Approval from the University of Toledo institutional review board (IRB) was obtained prior to implementing the protocol. The objective of this evidence-based project was to examine the current knowledge level and disease management behaviors of epilepsy patients in an out patient clinic setting and to measure the effectiveness of implementing a self-management protocol using the Epilepsy Self Management Scale (ESMS). The project leader met with the registered nurses (RNs), clinic manager and the neurologist to discuss protocol implementation. Input from the neurologist and RNs were elicited in writing the epilepsy educational sheet and in choosing the information placed in the educational packets. The project leader met one on one with the RNs weekly to screen the new patients scheduled in the epilepsy clinic. During these strategic weekly meetings the implementation process was reviewed and changed to facilitate the practice change.

The educational packets were assembled weekly by the project leader depending on the number of new patients scheduled. The packets were kept in the epilepsy educational closet for easy access. The *Medicines for Epilepsy* pamphlet was chosen because it has all anti epileptic medicines listed with pictures of each pill and possible side effects. Patients need to know what their medications look like and potential side effects to monitor for when taking the medications. The *Type of Seizures* pamphlet clearly explains the different types of epilepsy. The packets were two pocket folders containing an informational letter explaining the evidence based project and the materials listed in Table 3.
The neurologist would page or call the nurse only if he identified a patient for the self management project. Patients were given the introductory letter explaining why the project was being done and explained the patient’s role in the project. Once the patient verbally agreed to participate, they were given the ESMS to complete. It usually took 10 - 15 minutes for the patient to complete the ESMS and demographic information sheet. Each survey was reviewed by the nurse for completion and understanding of the patient’s epilepsy and self management knowledge base. The nurse or nurse practitioner reviewed each item in the educational packet with the patient during the educational session.

Information regarding seizures, safety, medications, finances, employment, and driving were discussed with each patient.

During the first four weeks, the project leader conducted a follow up phone call to participants 10 to 14 days after their first appointment. Due to the difficulty in contacting patients because of wrong or disconnected phone numbers, and because patients reported no new questions or need for follow up information, it was decided to discontinue the follow up phone calls. Another practice change implemented was the addition of driving information in the educational packets for patients with epilepsy. This information was

<table>
<thead>
<tr>
<th>Epilepsy Self Management Scale Survey</th>
<th>Clinic phone numbers and hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy Educational Sheet</td>
<td>Medicines for Epilepsy pamphlet</td>
</tr>
<tr>
<td>Seizure Diary</td>
<td>Type of seizures pamphlet</td>
</tr>
<tr>
<td>Micromedics Medication Information sheet when new medication prescribed</td>
<td>Seizure safety information from the Northwest Ohio Epilepsy Center</td>
</tr>
</tbody>
</table>
added because most patients were documenting driving as the activity most affected by seizures. An order form for a medical bracelet was added to the educational packets after many patients reported not wearing or carrying any information identifying them as having epilepsy.

Patients were enrolled in the project from the middle of March until the end of June 2011. The enrollment period was lengthened due to poor patient return for the second survey appointment. Twenty patients were enrolled in the evidence based project. Fourteen patients completed both the pre and post surveys. The six patients who did not complete the post survey were considered lost to follow up after three attempts to contact them were made and no return response was received.

**Project Findings**

**Outcomes**

In this project, 14 participants completed both the pre- and post-intervention ESMS survey. Six participants completed only the pre-intervention ESMS. For participants who completed both the pre- and post-intervention surveys, the total mean scores as well as the mean scores for each if the five factors were calculated: (a) medication management, (b) information management, (c) safety management, (d) seizure management, and (e) lifestyle management (see Table 4). Data were analyzed using the Statistics Package for Social Sciences (SPSS, Version 17.0) to determine knowledge-related outcomes of the implementation of the protocol. Level of significance was set *a priori* at $p < 0.05$ to reduce the chance of a type I error. Descriptive statistics (mean, standard deviation [SD], and number and percentages for categorical variables) were obtained for each demographic, outcome, and intervention-related variable.
Table 4

<table>
<thead>
<tr>
<th>Variables</th>
<th>Pre-test M (SD) (n=14)</th>
<th>Post-test M (SD) (n=14)</th>
<th>t score</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score</td>
<td>143.86 (15.10)</td>
<td>153.36 (12.70)</td>
<td>-2.677</td>
<td>.019*</td>
</tr>
<tr>
<td>Medication management</td>
<td>45.71 (3.85)</td>
<td>46.36 (3.65)</td>
<td>-1.236</td>
<td>.238</td>
</tr>
<tr>
<td>Information management</td>
<td>19.78 (7.39)</td>
<td>24.143 (5.54)</td>
<td>-2.851</td>
<td>.014*</td>
</tr>
<tr>
<td>Safety management</td>
<td>34.00 (3.86)</td>
<td>35.57 (2.84)</td>
<td>-1.388</td>
<td>.189</td>
</tr>
<tr>
<td>Seizure management</td>
<td>29.21 (4.44)</td>
<td>31.86 (2.79)</td>
<td>-2.757</td>
<td>.016*</td>
</tr>
<tr>
<td>Lifestyle management</td>
<td>18.71 (4.23)</td>
<td>19.71 (3.62)</td>
<td>-1.035</td>
<td>.320</td>
</tr>
</tbody>
</table>

Note. *p < .05

The differences in the ESMS scores for the new patients before and after intervention were compared by conducting independent sample t-tests and paired sample t tests the mean scores for all variables increased from the pre- to the post-intervention assessment and were statistically significant for the total pre- and post-intervention score (p=.019), information management (p=.014) and seizure management (p=.016). These results suggest that people with epilepsy who undergo educational intervention (a) increase their communication with friends, family and health care providers about their epilepsy and (b) avoid situations that cause seizures, use systems to manage their disease, and follow instructions given by their healthcare providers. The mean question score for the total ESMS (4.05) in our study was similar to total mean scores in other epilepsy patient studies (McAuley et al., 2008)
Differences on the baseline measurement between the six participants who completed only the pretest and the 14 participants who completed both the pre and post tests were explored. Scores overall all and on categories except life style management on the ESMS at baseline were found to be higher for those who completed both the pre and post tests. Refer to Table 5 for the differences in the means of the two groups. These results may indicate that those who completed both tests are more committed in general to management of their condition, thus the higher scores. This also raises the concern for those who did not complete the follow up as a group who needs to be targeted. Exploration of approaches to establish the follow up need to be explored.

Table 5
*Differences in mean scores on pre test of the group that completed only the pre-intervention survey and the group that completed both the pre- and post-intervention assessments.*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean scores of those taking Pre-test Only M (SD) (n=6)</th>
<th>Mean scores of those completing Pre-test and Post-test M (SD) (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>133.00 (19.14)</td>
<td>143.86 (15.10)</td>
</tr>
<tr>
<td>Medication Management</td>
<td>40.83 (6.70)</td>
<td>45.71 (3.85)</td>
</tr>
<tr>
<td>Information Management</td>
<td>18.50 (6.89)</td>
<td>19.79 (7.39)</td>
</tr>
<tr>
<td>Safety Management</td>
<td>29.67 (5.08)</td>
<td>34.00 (3.86)</td>
</tr>
<tr>
<td>Seizure Management</td>
<td>27.67 (5.98)</td>
<td>29.21 (4.44)</td>
</tr>
<tr>
<td>Lifestyle Management</td>
<td>18.71 (3.44)</td>
<td>20.67 (4.23)</td>
</tr>
</tbody>
</table>

*Note.* Although the level of significance was set *a priori* at $p < 0.05$, results indicated by an “*” suggest practical or clinical significance at the $p < .05$ level.

**Practitioner Evaluation of the Implementation Process**

A practitioner evaluation survey was created by the project leader to improve and increase understanding of the implementation process. The project leader met weekly with the neurologist and RNs to discuss implementation logistics. Both the neurologist and RNs evaluated
the protocol’s step-by-step process on a weekly basis. Responses related to the usability of educational information were discussed by the nurses and neurologist throughout the implementation process. During the weekly meetings, nurses provided suggestions for improving the protocol implementation. The suggestions made by the nurses were integrated into the educational intervention throughout the duration of the project. Changes to the educational intervention were implemented on an as-needed basis depending on the evaluations. For example, comments from one RN indicated a knowledge gap regarding one participant’s specific seizure disorders and a need to correctly identify patients’ seizure types prior to the educational session. Based on this feedback, an additional step was added to the implementation protocol. This step included asking the neurologist what type of seizure disorder, generalized or partial, the patient suffered from. The *Type of Seizures* pamphlet was then used to help explain each patient’s seizure type.

Nurses and the neurologist reported that the educational information provided to patients was timely and applicable in the outpatient neurology clinic. By reviewing the ESMS surveys on a weekly basis, the nurses and neurologist were able to identify patient needs and address these needs in a timely manner. The neurologist recommended continuing the epilepsy self-management protocol. The nurses and neurologist indicated that the protocol was easy to understand, and having the educational material centrally located enabled them to access it easily.

**Patient Evaluation of Implementation Process**

A patient evaluation form was developed by the project leader in order to better understand patients’ viewpoints regarding the implementation process and the educational sessions related to the epilepsy self-management education protocol. Thirteen out of the fourteen
participants completed the patient survey. The survey was completed at the end of patients’ second appointment and after they had completed the post-intervention ESMS. The 13 patients who completed the evaluation forms indicated that they received both verbal and written educational information about anti-epileptic medication, seizure type, and safety and that the information was easy to read and understand. Additional patient education information was added to the packets according to issues identified by the patients as well as comments or concerns that arose after reviewing the completed surveys. All participants who completed the patient survey recommended the epilepsy self-management protocol be given to all patients.

**Final Summary Statements**

This evidence-based research project was conducted to explore the implementation of an epilepsy self-management protocol to better understand epilepsy patients’ current knowledge level and improve their disease management behaviors. In the present project, the ESMS was used to measure the effectiveness of implementing a self-management protocol in an outpatient clinic setting. Robinson et al., (2008) defined epilepsy self-management as “a class of adaptive behaviors used by persons to control their seizures” (p. 523). Research has indicated that people with epilepsy want educational information about epilepsy in general, driving, lifestyle management, employment, seizure types, medication, side effects from medication, treatment options, and seizure control (Rajpura & Sethi, 2004). Kobau and DiIorio (2003) found that increasing the awareness and capabilities of patients to manage their diseases has become an increasingly widespread practice in the health care community.

The results of the present project suggest that patients need and want information about safety, seizure and medication management. Patients reported that understanding
safety information, such as the risks of taking a bath or climbing a ladder, was helpful. This supports the findings of May and Pfafflin (2002) which stated participants in an epilepsy educational program showed improvement in knowledge and coping with epilepsy. Being aware of the nuances of their seizures and knowing how to manage them empowers patients. Increased awareness of safety issues may prevent serious injuries or situations where patients can be harmed. Doughty et al (2003) also found that epilepsy patients have knowledge deficits in medication issues and causes of epilepsy. In this project 80% of the participants took their medication most of the time or always at the same time every day. Participants reported taking their seizure medication as the doctor prescribed, but sometimes forgetting a dose when away from home or when they were too tired at night. Nurses can be helpful in educating patients about using pill boxes to remind them to take their medications. Prior to the educational intervention most participants were unaware of the difference between partial or focal epilepsy and generalized epilepsy. They just knew they had epilepsy but were not able to clearly explain their specific seizure type. This finding supports the research of Doughty et al., 2002, who reported most epilepsy patients know general information about epilepsy but lack knowledge about their own health condition.

Pryse-Phillips et al. (1982) found that giving epilepsy patients information both verbally and in written form was the most effective way to improve their knowledge about their disease and treatment plan. However, most of the patients in this study seemed to glean more information from the face-to-face interaction with nurses than by reviewing the educational information sent home with them. When questioned about the written literature they had received in the epilepsy self management protocol educational folder, 50% of the
patients had not reviewed it. When giving patients written educational information more may not be better. Providing patients with clear and concise information about epilepsy enables them to cope with their disease, and it also creates an environment that enables them to verbalize their worries and fears about epilepsy (Cochrane, 1995). The epilepsy nurse specialist assisted the general communication process between the patient and health care providers while meeting the educational needs of patients (Rajpura & Sethi, 2004). Participants in this study did not wear or carry any information identifying them as a person with epilepsy. The participants also reported infrequent participation in support groups or talking with others who also suffer seizures. During the educational intervention session, the nurses encouraged participants to join a support group or to use educational web sites such as Epilepsy Foundation or “Talk about it”. The Epilepsy Foundation web site has patient, caregiver and healthcare provider information about living with epilepsy. “Talk About It” web site was started by the actor Greg Gumbel because his son has epilepsy. The web site has interactive vignettes about epilepsy. Popular television and movie actors participate in the educational vignettes.

Coster and Norman (2009) confirmed that nurses are the most likely group of health care providers to conduct patient education. Evidence indicated that epilepsy patients have more self-efficacy related to healthy medication management behaviors than they do healthy lifestyle management behaviors (Kobau & DiIorio, 2003). In the epilepsy self-management protocol project, the participants who completed both the pre- and post-intervention ESMS, compared to participants who completed only the pre-intervention ESMS, scored higher in all categories except lifestyle management. Lifestyle management is defined as the “knowledge, attitudes, skills, and behaviors required to promote general
physical and mental health and a good quality of life (Robinson et al., 2008, p. 523). Being sleep deprived, not exercising regularly and increased stress are lifestyle management behaviors associated with increased seizure frequency. Stress and lack of sleep are the two most common causes of seizures identified by epilepsy patients (Robinson et al., 2008). Half of the participants in this project never or rarely performed stress reducing behaviors, such as relaxation therapy, guided imagery or self hypnosis. Seventy percent of the participants made sure they got enough sleep. DiIorio and Henry, 1995; DiIorio, Hennessey, et al., 1996; DiIorio, Shafer, Letz, Henry, Schomer and Yeager, 2004) identified a positive correlation between self-efficacy and self-management behaviors in patients with epilepsy. According to Bandura, successfully overcoming obstacles enhances an individual’s self-efficacy, so epilepsy patients who perceive a high level of self efficacy are likely to demonstrate improved disease management (DiIorio, Shafer, Letz, Henry, Schomer and Yeager, 2006). McAuley et al., (2008) using a similar sample of 50 patients assessed if epilepsy self management behaviors differed depending on the level of seizure control. The patients completed the ESMS scale one time either at home or in the epilepsy clinic. Even though the patients did not receive an intervention and the question distribution was slightly different, the total mean scores were comparable to this project. McAuley et al., (2008) mean question score for the total ESMS (3.7) was very close to the total pre-test mean score (3.78) for this project. Other studies (DiIorio, Shafer, Letz, Schromer and Yeager, 2006; DiIorio, Faherty, 1992) using the ESMS had similar patient scores too.

In this epilepsy self-management project, the educational intervention emphasized aspects of the participants’ behavior that they can control, providing the patients with a
starting point for changing their behavior and providing a foundation to support future and ongoing positive behaviors (Srof & Velsor-Friedrich, 2006).

Unfortunately, there is a paucity of research data available on the benefits of providing patient education about disease management and the effectiveness of nursing interventions for patients with chronic illnesses (Coster & Norman, 2009). Clearly, this is an area that would benefit from additional research. Additional research in this area needs to be conducted because patients who possess increased knowledge about their disease feel more capable of performing self-management behaviors; in addition, they experience improved health outcomes and a higher quality of life (Cochrane, 1995; DiIorio and Henry, 1995; DiIorio, Hennessey, et al., 1996; DiIorio, Shafer, Letz, Henry, Schomer and Yeager, 2004, 2006; DiIorio, Reisinger, et al., 2009). Future research recommendations would include the effects of epilepsy on the family unit.

Recommendations

The evaluation of the protocol by the project leader, team members, and participants helped to identify a few recommendations for implementing the epilepsy self-management protocol in the future. The recommendations address the implementation of the protocol and the educational sessions provided to the epilepsy patients. In January 2011, the American Academy of Neurology (AAN) published evidence-based quality measures for the treatment of people with epilepsy. These quality measures provided recommendations for improving epilepsy patient care and disease management. Information from this article was also integrated into the epilepsy self-management protocol recommendations.

Another recommendation for implementing the protocol is to meet with the team members as a group and not individually, as we did initially for this project. The initial plan was
to meet with the clinic staff (RNs and MAs) together and present a PowerPoint presentation about implementing the epilepsy self-management protocol. However, due to scheduling conflicts and lack of time, a group meeting was not scheduled, and individual meetings were conducted in order to facilitate the implementation. A group meeting would have encouraged more frequent and clear communication among team members as well as a more thorough exchange of ideas. A group meeting may have improved the implementation process more than meeting individually with team members. When the epilepsy self-management protocol is permanently implemented, the project leader plans to meet with the other two epileptologists to discuss the best way to incorporate the protocol into their epilepsy clinics. Two of the Neurology Residents inquired about the epilepsy self-management protocol and the ESMS survey, indicating that practitioners could do a better job of including and educating other practitioners about the protocol in the future.

Regarding the patient educational material, updated information about driving restrictions related to seizures will be added. In the initial educational packet, an educational sheet included a sentence about driving but did not include specific information about driving restrictions in the state of Ohio. An informational sheet on driving and epilepsy was added to the packet after several patients indicated driving was a very important activity that had been affected by their seizures. A pamphlet about epilepsy and driving from the Epilepsy Foundation may be added to the literature packet, but if cost is an issue, an information sheet with specific state laws should be written and reviewed by team members before distributing it to patients.

Another recommendation would be to use the ESMS as an educational guide and tool when teaching patients about lifestyle, seizure, safety, medication and information management. The ESMS included an information management statement discussing whether patients carried
or wore information identifying them as a person with epilepsy. A minority of patients reported wearing a medical alert bracelet. Therefore, information should be added to the patient educational packet about how to obtain a medical alert bracelet to ensure that all epilepsy patients carry information about their diagnosis with them at all times. This step is important because if a person with epilepsy is found unconscious or confused, anyone assisting him or her will be aware of about their epilepsy diagnosis.

Another recommendation regarding patient educational information is to incorporate the AAN epilepsy quality measure recommendations in the information sheet provided to each new patient and in the medical record documentation. The AAN recommends that health care providers inform patients about their seizure type and document seizure frequency during each clinic visit. The recommendation to keep a seizure diary is already part of the educational packets. Inquiring about side effects of taking anti-epileptic medication and providing appropriate counseling are additional quality measures that can be taken in order to improve the delivery of epilepsy patient care.

Information gleaned from and discussed with patients about medication side effects must be documented in the medical record for future reference. Patients are given written educational information on each anti-epileptic drug prescribed for them, but health care providers need to be more consistent in reviewing the potential side effects with their patients.

Another recommendation regarding patient care is to educate patients about medication and safety issues, such as bathing, driving, and using power tools, during their first appointment. When comparing the difference between those participants who completed only the pre-intervention survey and those participants who completed both the pre- and post-intervention surveys, in all categories except lifestyle management, scores were higher in the group that
completed both surveys. The difference between those who completed only the pre-intervention survey and those who completed both the pre- and post-intervention surveys

The final recommendation is to implement the epilepsy self-management protocol as a permanent clinical practice policy in this particular neurology outpatient clinic. Incorporating this practice as a formal policy is useful and feasible. A summary of the final recommendations for materials to be included in the epilepsy self-management packets is included in Table 6.

Table 6

<table>
<thead>
<tr>
<th>Epilepsy Self Management Patient Packet Materials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy Self Management Scale Survey</td>
</tr>
<tr>
<td>Epilepsy Educational Sheet</td>
</tr>
<tr>
<td>Seizure Diary</td>
</tr>
<tr>
<td>Driving and Seizures Handout</td>
</tr>
<tr>
<td>Medical Alert Bracelet Order Form</td>
</tr>
</tbody>
</table>

Limitations

This evidence-based project assessed the development and the implementation of an epilepsy self-management protocol in an outpatient setting. However, during the implementation of the project, several limitations were identified. One limitation included the fact that one of the RNs failed to complete the required institutional review board (IRB) training; therefore, only one RN was available to conduct all new epilepsy patient clinics during the majority of the implementation phase. Because the IRB training requirements were not met, the IRB paperwork for approval was delayed for approximately two weeks. A decision was made to remove the RN
from the IRB paperwork at that time in order to keep the project moving forward and to avoid additional delays resulting from failures to complete paperwork. Once she completed the training, an amendment was provided requesting that she be added to the team.

A second limitation included insufficient patient follow-up reporting during the second appointments. In short, some patients failed to complete the post-intervention ESMS. Six patients in total did not complete the second survey. The project leader placed numerous phone calls to these patients in order to reschedule their appointments and to make contact with patients who missed their appointments. After three phone calls without any response, the patient was considered inaccessible for follow-up reporting. Because of the difficulties contacting patients to schedule follow-up appointments, there was variability in the number of days between when patients completed the first survey and when they completed the second survey. The number of days between pre- and post-survey completion ranged from 5 to 56. This difference in time between surveys may have affected the results obtained.

A third limitation was the fact that the intervention changed during the implementation protocol as a result of suggestions made by the nurses and neurologist. A fourth limitation was there were only 14 participants who completed the post test. These participants may represent a more committed group than those who did not complete the post test. It is unknown if these 14 participants represent the general out-patient group. A fifth limitation was there are few randomized control trials looking at epilepsy self management. Majority of the research studies were descriptive, survey studies.
Conclusions

Epilepsy and self-managed care have been identified as significant public health concerns (Barkley, 2003). Self-management should be considered a path toward behavioral change that supports health. Health care providers caring for people with epilepsy must facilitate the development and research of self-management programs (Barkley, 2003). Researchers (DiIorio, Hennessey, et al., 1996; Risdale, Morgan, et al., 1999; Risdale, Kwan, et al., 2002) have found that patients preferred talking with nurses about social and lifestyle management issues. Patients also highly valued nurses who coordinated additional health services. Previous research findings illustrate epilepsy self-management as a variety of behaviors and actions utilized to manage seizures, medications, safety, and lifestyle issues (Barkley, 2003; Buelow & Johnson, 2000; Cochrane, 1995; Dilorio and Henry, 1995; Dilorio, Hennessey et al., 1996; Dilorio, Shafer, Letz, Henry, Schomer and Yeager, 2004, 2006; Elliott & Shneker, 2008; Kendall et al., 2004; McAuley et al., 2008; Pramuka et al., 2007; Risdale et al., 1999, 2002). Pender's health promotion model (HPM) (Pender, Murdaugh & Parsons, 2011) and Rogers’ (1995, 2003) diffusion of innovations theory provide the theoretical frameworks in guiding the implementation and evaluation of this evidence based project.

In order to effectively care for epilepsy patients, it is imperative that healthcare providers increase their understanding of patients’ motivations to engage in specific self-management behaviors (Unger & Buelow, 2009). The evidence from the present evidence-based research project supports the educational effectiveness of nurses specializing in epilepsy care and self-management programs for people with epilepsy. This self-management project will improve epilepsy patient educational needs and the role of self-efficacy. This evidence-based project, Implementation of a Self Management protocol, needs to be realized because at any stage in life,
health-promoting behaviors integrated into the lifestyles of epilepsy patients leads to improved overall health and generation of a better quality of life (Carreno, et al., 2006).
References


(Due to copyright issues Appendix A is pages 59-61)
**Epilepsy Self Management**

Instructions: The following statements describe what people do to manage their epilepsy. Please circle one number for each statement to show how often you do the following. As you answer the questions, please think about your activities in the past year.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Most of the Time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>IM 1.</td>
<td>I write down how often I have seizures and when they occur.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>LM 2.</td>
<td>I do things such as relaxation, guided imagery, and self hypnosis to manage stress.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>IM 3.</td>
<td>I call my doctor when I think I am having side effects from my seizure medication.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*MM 4.</td>
<td>When my seizure medication is running out, I spread out the time between doses.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>IM 5.</td>
<td>I keep a record of the types of seizures I have.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*SM 6.</td>
<td>I stay out late at night.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>IM 7.</td>
<td>I keep track of the side effects of my seizure medication.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*MM 8.</td>
<td>When my seizure medication is running out, I take less medication at each time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>MM 9.</td>
<td>I take my seizure medication the way my doctor orders it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SeM 10.</td>
<td>I stay out of situations that might cause a seizure.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SeM 11.</td>
<td>If I am going away from home, I take my seizure medication with me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SeM 12.</td>
<td>I call my doctor if I am having more seizures than usual.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>LM 13.</td>
<td>I make sure I get enough sleep.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Copyright © 2010 Colleen DiIorio*
<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Most of the Time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LM 14. I do things that I enjoy to help manage stress.</strong></td>
<td>1</td>
<td>2</td>
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<td>5</td>
</tr>
<tr>
<td><strong>SeM 15. I have a way to remind myself to take my seizure medication.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>MM 16. I take my seizure medication at the same time each day.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*<strong>SM 17. I would go swimming alone.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>LM. 18. I do things such as relaxation, guided imagery, and self hypnosis to keep myself from having a seizure.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>SeM 19. When the doctor orders blood tests, I have them done.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>IM 20. I wear or carry information stating that I have epilepsy.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*<strong>MM 21. I have to put off having my seizure medication refilled because it costs too much money.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>LM. 22. I get enough exercise.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*<strong>SM. 23. I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*<strong>MM 24. I miss doctor or clinic appointments.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*<strong>MM 25. If I had side effects from the seizure medications, I would skip a dose without asking my doctor.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td><strong>SM 26. I take showers instead of baths.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
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<tr>
<td><strong>MM 27. I plan ahead and have my seizure medication refilled before I run out.</strong></td>
<td>1</td>
<td>2</td>
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<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Activity</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Most of the Time</td>
<td>Always</td>
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<tr>
<td>*MM 28. I miss doses of my seizure medication because I do not remember to take it. ☐</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SM 29. I keep the temperature of the water in my home low enough so I do not get burned.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*MM 30. I skip doses of seizure medication. ☐</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SM 31. I check with my doctor before taking other medicines. ☐</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>SeM 32. I stay away from things that make me have seizures.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>LM. 33. I eat regular meals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*SM 34. I climb objects such as high stools, chairs, or ladders.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>IM 35. I talk with other people who have epilepsy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>*SM 36. I drink a lot of alcoholic beverages such as beer, wine, and whiskey.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>IM 37. I participate in a support group for persons with epilepsy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>IM 38. I practice what to do during a seizure with my family and friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>

**Subscales:**
- MM = Medication management
- IM = Information management
- SM = Safety management
- SeM = Seizure management
- LM = Lifestyle management

* Reverse code
Appendix B

We have reviewed several journal articles about epilepsy and its effect on patients. In our literature review we discovered certain topics or issues that seem to be common to all people with epilepsy. We decided to give our patients some of this information in order to answer any questions as well as to help our patients better manage their epilepsy.

**Lifestyle Management**

**DRIVING**
Patients who are seizure free have no driving restrictions. If you have a breakthrough seizure you are not allowed to drive for 6 months.

**EMPLOYMENT**
Having seizures does not prevent you from working. If you have seizures, there may be work restrictions such as no working at heights and around heavy machinery. Our social workers can assist patients with ways to find a job.

**SLEEP and STRESS**
Being sleep deprived and stressed may increase your chance of having seizures. We recommend at least 7-8 hours of sleep per night. Exercise and relaxation therapy, such as meditation or yoga, help lessen stress and promote better sleep.

**FINANCES**
Our social workers are available to help patients who need financial assistance. We refer patients to The Ability Center, Legal Aid and financial counselors at University of Toledo Medical Center.

**Medication Management**
Always take your seizure medication regularly. Never abruptly stop your medication; this may cause an increase in seizures, which can be dangerous for you. It is important to be honest with your doctor or nurse, especially if you are not taking your medication as prescribed or if you are having side effects. If you miss a medication dose call your doctor. Give your memory some help, use pill boxes, watches with alarms or notes to remember your pills. Taking your medications at the same time you perform daily tasks such as brushing your teeth or bedtime may help too.

If you are started on a new medication, you will receive written information to take home for review. If you have problems paying for your prescriptions, we can prescribe generic medication or you may qualify for our patient medication assistance program.
Appendix B (cont’d)

Seizure Management
There are many different types of seizures. People may experience just one type or more than one. The kind of seizure a person has depends on which part and how much of the brain is affected by the electrical disturbance that produces seizures. Experts divide seizures into generalized and partial seizures. In generalized seizures, both sides of the brain are affected. With partial seizures the electrical disturbance is limited to a specific area of one side of the brain.

Treatment Options
Your health care team is responsible for evaluating your condition, prescribing treatment options and working with you to make sure you are receiving the best treatment possible, so it’s important to keep the health care team updated as to how you are doing. Medications are one type of treatment, but there are also other treatments available such as epilepsy surgery and vagus nerve stimulator.

WEB SITES

www.epilepsyfoundation.org-- is a great resource for issues such as medications, patient assistance, educational information and communicating with professional who take care of epilepsy patients and other people with epilepsy

www.talkaboutit.org-- is a web site started by an actor named Greg Grunberg because his son has epilepsy. He has educational videos and interactive information about epilepsy.
### Evaluation Form for Epilepsy Self Management Protocol (Practitioner)

Please circle one: Physician  Nurse Practitioner  Nurse

1. Please answer the following with an X in the yes or no box:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were the Self management patient packets easy to find?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please evaluate the following:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usability of educational information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information was easy to understand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the information timely and applicable to epilepsy patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

Epilepsy Self Management Protocol Evaluation Form (Patients)

1. Please Answer the Following by marking an X in the yes or no box below

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you receive information about seizure medications and possible side effects?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you receive information describing the type of seizures you have?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you receive information about safety issues related to seizures, such as no driving until seizure free for 6 months?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the information you were given by the nurses easy to read and understand?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Please Evaluate the Following by marking an X in the yes or no box below

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you visit the Epilepsy web sites?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you find the web site information useful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the educational information you received about your seizure type, medication, safety issue helpful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would you recommend the Epilepsy Self Management Education Session be given to all patients?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>