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## Patient-Centered Migraine Management

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Patient-Centered Migraine Management

Systems Change Project  
Submitted in Partial Fulfillment  
of the Requirements for the Doctor of Nursing Practice Degree

St. Catherine University  
St. Paul, Minnesota

Ann Drapinski Rechtzigel  
May 2014

ST. CATHERINE UNIVERSITY  
ST. PAUL, MINNESOTA

This is to certify that I have examined this  
Doctor of Nursing Practice systems change project  
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Ann Drapinski Rechtzigel

and have found that it is complete and satisfactory in all respects,  
and that any and all revisions required by  
the final examining committee have been made.

Graduate Program Faculty

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Date

DEPARTMENT OF NURSING

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### Dedication

To my dad, Richard Drapinski, who passed away only four months into my Doctor of Nursing Practice endeavor. He was always supportive and proud of the educational accomplishments of his youngest daughter, whom he lovingly called “my Anna babe.”

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## **Executive Summary**

Migraineurs are people who suffer from migraine headaches— a widespread health condition which is considered to be one of the ten most disabling conditions in the world (WHO, 2012). Although migraine headaches are not typically life-threatening, they can cause significant levels of disability by producing incapacitating headache pain with a spectrum of associated symptoms including light and noise sensitivity, nausea and vomiting which can last anywhere from hours to weeks. This illness not only equates with high medical costs but it is also associated with a lost income adding up to a staggering \$12 billion per year in the United States (Lafata et al., 2004). Despite advanced technology and new medications, migraine headaches continue to cause substantial disability. Scholars believe that going back to the basics and providing the foundational migraine knowledge and skills to patients will significantly reduce migraine headache infirmity by empowering migraineurs to take control and manage their migraine independently.

The purpose of this study was to understand the perspectives of adult migraine patients and neurology providers at a Midwestern neurology clinic regarding migraine patient education. Furthermore, this study sought to develop a migraine patient education program that would provide the knowledge and skills necessary for patients to independently manage their migraine.

This systems change project involved two phases, using cross-sectional survey designs. Phase I surveys solicited information and opinions from the stakeholders—the migraine patients and neurology providers regarding the current methods of migraine patient education. Phase II involved developing, implementing, and evaluating a Headache Management Plan which was the first attempt at the Midwestern neurology clinic to provide a migraine patient education program which was patient-centered and evidence-based using stakeholder input.

Phase II survey results from both migraine patients and neurology providers were overwhelmingly positive with regard to participants being able to understand the Headache Management Plan, allowing patients' to be more actively involved in the planning of their treatment, providing the knowledge and skills to better manage migraine at home, and the rating of the overall experience with the Headache Management Plan.

Although the findings of this pilot study were very optimistic, the study was limited by marginal migraine patient survey responses in Phase I and a small sample size in Phase II of the trial with minimal representation of diverse populations. Thus, generalization of these conclusions could not be made to all adult migraine patient populations in the neurology clinic. Future studies are needed to further evaluate the method and content of this migraine patient education quality improvement initiative.

## **Chapter 1**

### **Introduction**

Headache is one of the most common diagnoses in primary care and neurology clinics and migraine is one of the major subtypes. Despite new technologies and medications that have developed over the years, migraine headaches continue to cause substantial levels of disability (Hazard, Munakata, Bigal, Rupnow, & Lipton, 2009). This migraine disability translates into very high health care costs. Scholars believe that lack of education to inform patients about their complex treatment and lifestyle changes is a key issue hindering good migraine management (Katic, Krause, Tepper, Hu, & Bigal, 2010). The most common way of educating patients is by using generic written materials that may not be suitable for most people, particularly for those with low reading levels, language barriers, or cultural differences. Moreover, many of these resources do not take individual needs and preferences into account. This type of migraine patient education (PE) can heighten health care disparities and patient dissatisfaction (Kershaw, Mood, & Wilson, 2003; Wilson, 2009).

The aim of this systems change project was to develop a migraine PE program that provided patients with the knowledge and skills necessary to combat migraine headaches by increasing their involvement in decision making and empowering them to be active participants in their own care (Barry & Edgman-Levitan, 2012). The educational process had to be patient-centered to ensure that all diverse populations had equal opportunity to obtain migraine PE; consistent so all migraineurs would have the same educational circumstances; time efficient for neurology providers to use, and evidenced-based so that they would have confidence in a new PE process that would provide the best quality and value to the clinic's most important individual—the patient.

### **Background and Significance**

Migraine is a widespread health condition affecting people of all races, ethnicity, and educational levels. According to the study, 'Lifting the Burden: The Global Campaign to Reduce the Burden of Headache Worldwide' (World Health Organization [WHO], 2004), the percentage of the adult population with active headache disorders in general is 46%, while 11% are migraine. Although migraine headaches are not typically life-threatening, they can with little warning cause significant levels of disability producing incapacitating headache pain and associated symptoms of photophobia, phonophobia, nausea and vomiting which can last anywhere from hours to weeks. Episodic migraine can become intractable for some. In the Global Burden of Disease Study of 2004, migraine accounted for 1.3% of years lost to disability, and headache disorders were considered one of the ten most disabling conditions and were one of the five most disabling for women (WHO, 2012).

### **Economics of Migraine**

Migraine disability comes with a high price. When the costs of migraine to society are analyzed, they are categorized as either direct or indirect costs. The direct costs are those related to the use of medical resources, including provider visits for diagnosis or treatment, emergency room (ER) visits, diagnostic procedures, and medications. These costs can vary greatly due to methodological differences, severity of disease, operational definition of migraine, and medications and services included. The estimated annual United States (US) health care costs in 2010 for migraine associated with outpatient visits were \$3.2 billion, ER visits were \$700 million, and inpatient hospitalizations were \$375 million (Insinga, Ng-Mak, & Hanson, 2011). Hazard et al. (2009) found total costs from pharmacy and medical care was \$7,007 per patient per year for migraineurs versus \$4,436 for nonmigraineurs. There are also many direct non-

medical costs that patients and their families incur related to incidentals such as gas and transportation. These costs are likely underestimated given the existing level of migraine under-diagnosis and under-treatment. Although these direct costs are substantial, they are only a fraction of the disease's overall cost to society.

The total indirect cost of migraine was \$12 billion per year (Lafata et al., 2004). This common neurological condition is associated with substantial lost time from work that typically manifests itself in a person's second or third decade of life and continues during an individual's most productive years (Jensen & Stover, 2008). These figures do not include unemployment or underemployment as well as those who do not work outside the home. It also does not include the intangible costs of lost time away from family and societal activities, pain and suffering, and reduced quality of life. The argument for better migraine management is based on extensive evidence that effective migraine care can reduce absenteeism and improve productivity among working individuals (Lafata et al., 2004).

### **Patient Education**

Many headache specialists who study migraine believe that migraine impairment could be greatly decreased if patients had the appropriate education to manage their illness independently (Katic et al., 2010). Understanding the triggers responsible for setting migraine in motion and the proper use of medication could greatly reduce disability and improve quality of life. Here lies the problem: the most common ways of teaching PE migraine skills is by either using verbal exchange at an office visit or by using generic complex written information which is not suitable for most Americans and especially those with low health literacy.

In fact, according to the US Department of Health and Human Services, Office of Disease Prevention and Health Promotion (n.d.), only 12 percent of adults have proficient health



literacy. Healthy People 2010 (n.d.) defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 2). Lower levels of literacy are found across the demographic spectrum but are more common in people with limited education, low English skills, and low income; reduced literacy is also found among the elderly and people from racial or ethnic minority groups. The health literacy problem is further exacerbated by the fact that most patients immediately forget up to 80% of what they are told during a health care office visit and nearly half of the information recalled is incorrect (Kessels, 2003). If there is meager understanding or insufficient recall of PE information, then adherence and outcomes related to treatment will be poor.

To help improve comprehension and retention of PE information, Vickers (2012) from the Mayo Clinic Patient Education Research Program suggests “utilizing written patient materials which incorporate the principles of plain language” (p. 51). However, researchers suggest that information alone is not always sufficient, especially when encouraging behavior change such as self-management in chronic disease. Using interactive teaching strategies designed to involve patients in problem solving and to address their cultural, socioeconomic, educational, and psychological needs will promote self-care (Anderson & Funnell, 2005; Philis-Tsimikas et al., 2004; Stone, Pound, Pancholi, Farooqi, & Khunti, 2005). Tailoring PE to the individual using their life experiences will ensure that the content provided is relevant for the needs of the person (Anderson & Funnell, 2010; Tang, Funnell, Brown, & Kurlander, 2010). This type of framework is called patient-centered care.

### **Patient-Centered Care**

Modern healthcare has been slowly evolving from the traditional disease-centered model of care to a more patient-centered model which provides a more individualized approach to patient education and promotes responsibility for self-care in living with chronic disease (Anderson & Funnell, 2010). The concept of patient-centered care was first introduced to the nation in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm* (Richardson et al., 2000) as one fundamental way of improving the quality of care in the US. The IOM (Richardson et al., 2000) defined patient-centered care as: “care that is respectful of and responsive to individual patient preferences, needs, and values and that ensures that patient values guide all clinical decisions” (p. 3). This definition highlights the importance of patient involvement in decision making which empowers them to be an active participant in their own care. This approach to care promotes self-responsibility (Barry & Edgman-Levitan, 2012). According to Epstein, Fiscella, Lesser and Stange, 2010, the attributes of patient-centered care are not only desirable, but are crucial to delivering health care that will reduce cost and improve quality and value.

One way of increasing quality and value in the specialty of neurology is by providing a patient-centered approach in educating patients with migraine headaches. This strategy can deliver effective self-management by empowering the patient and supplying the culturally sensitive knowledge and skills necessary to independently care for their migraine (Bastable, 2006). The term empowerment in this context is defined as “educating and encouraging patients to expand their role in decision-making, health-related behaviors, and self-management of care” (Dreeben, 2010, p. 52) Patients who are actively involved in their own care make better decisions

about their health and obtain clarity about their goals, values, and motivation. Ensuring that all migraineurs are provided with patient-centered PE is a social justice issue.

### **Migraine Management and Social Justice**

This systems change project, guided by the principles of social justice, originated as a quality improvement journey for a Midwestern neurology clinic. The diagnosis of migraine was chosen because patients with headache are one of the largest clinic populations. The process began by reviewing the literature and uncovering the shocking statistics that only 12 percent of adults have proficient health literacy and nearly nine out of ten adults lack the skills needed to manage their health (US Department of Health and Human Services (HHS), Office of Disease Prevention and Health Promotion, n.d.). Moreover, the current clinic PE materials for migraine were limited and assessed to be at a grade 14 reading level, according to the Simplified Measure of Gobbledygook (SMOG) readability calculator score (National Institute of Adult Continuing Education [NIACE], n.d.).

These health literacy statistics, along with the high reading levels of the migraine educational materials created concern as to whether most migraine patients could fully comprehend the information, particularly those of diverse populations. This disparity threatens the very principles of social justice and defies human dignity. It is the health care provider's responsibility to ensure that health information is understood by all of their patients. The American Nurses Association (ANA) Code of Ethics for Nurses endorses the need for nurses to collaborate to educate and care for all people, no matter their educational level, culture, values and practices (2001). This can be achieved by using patient-centered care.

This quality improvement migraine education initiative clearly advocates patient-centered care, which treats every adult migraine patient individually. The empowerment that patient-

centered migraine education brings will allow patients to be successful in living with their chronic disease by becoming active participants and being equipped with the necessary knowledge and skills to make good decisions regarding their health. This type of migraine management has the potential for reducing emergency room visits and lost time from work as well as decreasing incidence of medication overuse headaches and long-term complications of chronic migraine. Other outcomes include increasing patient satisfaction, quality of life, treatment adherence, and safety in migraine patients from all walks of life.

### **Problem Statement**

Headache is one of the most common diagnoses in primary care and neurology clinics and migraine is one of the major subtypes. Despite new technologies and medications that have developed over the years, migraine headaches continue to cause substantial levels of disability. According to migraine scholars, migraine related disability could be considerably reduced by emphasizing the patient's involvement in their own care and focusing on the patient's individual responsibility to manage their illness by helping them understand their diagnosis, treatments, and lifestyle changes (Katic et al., 2010). This sentiment was echoed by the Atlas of Headache Disorders and Resources in the World 2011 (WHO), noting lack of education as one of the key issues impeding good management of headache.

The setting of the systems change project was a Midwestern neurology clinic that, like most other health institutions, had always used the traditional disease-centered model of PE consisting of written PE materials for the care of migraine headache patients. Although written materials are by far the most frequently used tools for educating migraine patients, they may be unsuitable for a number of patients who cannot read or comprehend the materials. Development

of a patient-centered and evidence-based migraine PE program would provide efficient as well as consistent migraine education promoting patient responsibility.

### **Purpose Statement**

The purpose of this study was to understand the perspectives of migraine patients and neurology providers at a Midwestern neurology clinic regarding migraine PE. Furthermore, this study sought to develop a migraine PE program that would provide the knowledge and skills necessary for patients to self-manage their migraine.

### **Project Objectives**

1. Engage all stakeholders, including all neurology providers and migraine patients at a Midwestern neurology clinic to assess the current migraine PE.
2. Review relevant literature regarding migraine PE.
3. Create a patient-centered and evidence-based migraine management PE plan at a Midwestern neurology clinic based on stakeholder input and literature review.
4. Implement the migraine management PE plan pilot.
5. Evaluate the migraine management PE plan using stakeholder surveys.
6. Utilize the findings to further develop and refine the PE migraine management plan so that it can be used clinic wide.

### **Clinical Questions**

There were two clinical questions related to this systems change project. The first question posed was: In a Midwestern neurology clinic, do the current methods of PE provide the knowledge and skills necessary for patients to self-manage their migraine? The second question was: In a Midwestern neurology clinic, does a patient-centered and evidenced-based migraine

management PE plan provide the knowledge and skills necessary for patients to self-manage their migraine?

The significance of this systems change project is that it will ultimately change the way migraine patients are educated by building partnerships between patients and health care providers, bridging the health literacy gap in PE and giving back the responsibility to the patient. Going forward in Chapter Two there will be the endeavor's conceptual framework and review of the literature. Chapter Three will be a review of the project design, methodology, and pilot study. Chapter Four will set out the results for Phases I and II, and to conclude, Chapter Five will discuss the major findings and offer recommendations.

## Chapter 2

### Conceptual Framework and Literature Review

#### Dorothea Orem's Nursing Self-Care Nursing Deficit Theory

The conceptual framework known as the Self-Care Deficit Nursing Theory (SCDNT) from the influential nursing theorist Dorothea Orem (Bernier, 2002), provided guidance for the systems change project. Theory-based nursing practice provides a foundation for initiating the research process and guides nursing with the concepts and the goals.

Orem described nursing as a service of deliberately selected and performed actions to assist individuals to maintain self-care. She believed that individuals function and maintain life, health, and well-being by caring for themselves (self-care agency). When they are unable to meet their physical or emotional needs, a self-care deficit occurs which requires nursing intervention. The type of nursing care given depends on the degree of self-care deficit. Patients with chronic conditions such as migraine have needs for nursing care in the area of patient education in order for self-care to occur (Parker & Smith, 2010).

According to Orem's nursing framework, PE is a self-care nursing intervention which is considered a supportive education nursing system. It assists patients who are able to perform therapeutic self-care, yet need assistance in acquiring knowledge and skills through teaching and guidance. Orem's SCDNT refers to basic conditioning factors that can affect patient's capacity to care for themselves. These include age, gender, developmental state, health state, socioeconomic status, culture, family, resources, and environment (Parker & Smith, 2010). These factors will influence the particular values and paths toward self-care and need to be considered when delivering patient education to individuals with a chronic illness such as migraine (Kershaw et al., 2003). Providing patient-centered PE for individuals with migraine is consistent with the

SCDNT, allowing them to learn self-responsibility and accountability of their chronic health condition.

### **Malcolm Knowles' Adult Learning Theory**

Andragogy, also known as adult learning theory (ALT) was another theoretical foundation for this systems change project as it relates to learner-centered adult PE. Knowles believed that adult learners take responsibility for their own education and are independent and self-directed in the learning process. The role of the teacher is to engage the learner and be a facilitator of knowledge and a resource to the learner. Adults appreciate learning that incorporates the demands of their daily life with active problem-solving. Previous experience augments the learning process as they bring a wealth of rich experiences and life resources. They will integrate new ideas or concepts with information that they already know (Holton, Knowles, & Swanson, 2005).

Adult learners are mainly interested in immediate problem-centered approaches as compared to subject-centered methods. Life or work related situations are more appropriate for learning than theoretical approaches. Adult learners are primarily inspired to learn by internal drives than by external ones, although they are motivated by positive reinforcement and feedback by the educator (Holton et al., 2005). Because adults may have more difficulty remembering information, providing them with a specific outline will ensure greater retention of material. Using the complementary theoretical principles of the ALT and SCDNT as a foundation for the systems change project supported PE that was patient-centered and appropriate for all adult migraine patients.



### **Literature Review**

Migraine is an incurable neurological disorder which is known to cause significant disability. Educating patients about their illness and treatment would allow them to better manage their condition independently. There were two clinical questions related to this systems change project. The first question posed was: In a Midwestern neurology clinic, do the current methods of PE provide the knowledge and skills necessary for patients to self-manage their migraine? The second question was: In a Midwestern neurology clinic, does a patient-centered and evidenced-based PE migraine management plan provide the knowledge and skills necessary for patients to self-manage their migraine? Reviewing the research regarding PE helped to support and guide delivery of successful evidence-based migraine management.

### **Original Research**

The literature search related to the clinical questions was conducted using the following databases: CINAHL, Medline, PubMed, and Google Scholar using the keywords migraine, headaches, patient education, management and adult. Full text and peer-reviewed articles were used with years limited to the last eight years. Other filters included human subjects and English only. There were nine articles reviewed with the purpose of evaluating migraine PE interventions for adult migraine patients (see Appendix A). All of these studies showed positive outcomes. The study settings were in managed care, primary care, neurology clinics, and headache specialty clinics. From the analysis of the research studies, three major categories emerged: patient education methods, patient education content, and measuring patient education outcomes.

### **Patient Education Methods**

The nine migraine PE studies reviewed provided migraine PE content through written, group, and individual methods. These various approaches had the same goals of increasing patient participant's knowledge and skills to independently manage migraine.

**Written patient education materials.** The vast majority of the migraine PE studies reviewed used written materials as their main method of educating migraine patients. None of these studies cited grade levels of the materials provided. The research by Hu, Solomon, Conboy, Deml, & Markson (2004) and Campinha-Bacote et al. (2005) was targeting migraineurs in managed care systems and both were implemented by insurance companies, bypassing direct involvement of the medical providers and without direct patient contact. Both studies delivered generic written migraine educational brochures mailed on a monthly basis for six months. The Nicholson, Nash, & Andrasik (2005) study was similar to the Hu et al. (2004) and Campinha-Bacote et al. (2005) studies in that study participants were sent migraine educational materials in the mail, but in this study they were sent weekly and were personalized to each individual based on the established migraine diary information and initial assessment. Illiterate individuals were excluded from the study.

The primary care migraine education study by Smith, Nicholson, & Banks (2010) used written migraine educational materials but they were distributed by members of the health team at an office visit. The Bromberg et al. (2012) trial provided written materials via a web-based migraine education program. Non-English speaking individuals were excluded from the study. There were prerequisites of having computer competency and access as there was no human contact.

**Group patient education.** Rothrock et al. (2006), Cady, Farmer, Beach, & Tarrasch (2007), and Dindo, Recober, Marchman, Turvey, & O'Hara (2012) performed studies related to patient education using group education sessions. Each of these studies was very different in their methods and information provided. Rothrock et al. (2006) employed a group intervention at a headache specialty clinic using lay (non-professional) instructors as educators citing a very large migraine patient population and lack of resources to provide PE. The Cady et al. (2007) research took place at a headache specialty clinic using a 12 minute video of migraine pathophysiology with and without a nurse present. The study showed that having the presence of a nurse during the education video was more effective than no support. Dindo et al. (2012) used group education to teach an intense five hour workshop for migraineurs who had a comorbidity of depression, but only one hour was dedicated to migraine education. The other four hours was a behavioral therapy intervention.

**Individualized patient education.** The Matchar et al. (2008) migraine management research used the patient's choice of either group or individualized instruction for migraine PE. This program also incorporated migraine patient stakeholder involvement prior to the study by performing a needs assessment. The purpose of this study was to use midlevel providers working with a neurologist to offer treatment regimens to people in primary care which included an accurate diagnosis, appropriate treatment, and PE. The next section reviews patient education content.

### **Patient Education Content**

The nine migraine PE studies reviewed provided numerous types of PE information through written, group, and individual methods. There was an emergence of several themes from the content similarities.

**Understanding migraine.** All of the study interventions reviewed included education on understanding the diagnosis of migraine (Bromberg et al., 2012; Cady et al., 2007; Campinha-Bacote et al., 2005; Dindo et al., 2012; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006; Smith et al., 2010). Cady et al. (2007) presented a 12 minute video on the pathophysiology of migraine, identifying which phases of migraine are best to initiate migraine abortive treatment. Nicholson et al. (2005) and Rothrock et al. (2006) also provided information regarding when to treat migraine abortively with the emphasis on treating early in the course of migraine as leaving migraine progress in severity without proper treatment will lead to poor outcomes.

**Migraine trigger factors.** Another major component of PE content that was used by all of the studies reviewed was migraine trigger factors (Bromberg et al., 2012; Cady et al., 2007; Campinha-Bacote et al., 2005; Dindo et al., 2012; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006; Smith et al., 2010). These are defined as environmental, medication, emotional, physical, or dietary influences that can potentially cause a migraine attack and are different for each individual. Knowing a person's trigger factors is crucial to prevent migraine attacks.

**Migraine diaries.** Most of the migraine studies reviewed provided migraine diaries to participants (Bromberg et al., 2012; Campinha-Bacote et al., 2005; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006; Smith et al., 2010). It was unclear if Dindo et al. (2012) used migraine diaries as a part of their intervention. Tracking the migraine trigger factors through a diary is important in the evaluation of migraine headaches in order to get a better understanding of the relationship of the triggers to migraine occurrences. The migraine diary is also used to keep track of medication changes, keeping count of abortive

medications used, as well as the frequency and intensity of migraine which helps to provide accurate information to bring to clinic appointments.

**Lifestyle management.** Migraine trigger factors are often tied into an individual's way of life. Lifestyle management was another major content topic in almost all of the studies reviewed (Bromberg et al., 2012; Campinha-Bacote et al., 2005; Dindo et al., 2012; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006; Smith et al., 2010). The broad subject of lifestyle management included diet, exercise, sleep hygiene, and stress which can directly affect migraine frequency. Smith et al. (2010) also assigned cervical range of motion exercises with the purpose of loosening tight neck muscles which can trigger migraine.

Several of the studies placed a major focus on stress management by providing a behavioral skills component to the PE intervention. Nicholson et al. (2005) used relaxation and coping techniques. Matchar et al. (2008) offered relaxation techniques and referrals for other undefined behavioral therapies. Smith et al. (2010) provided biofeedback audio tapes. Bromberg et al. (2012) used relaxation and biofeedback techniques. Dindo et al. (2012) took the stress management emphasis one step further, offering a four hour long session on Acceptance and Commitment Training (ACT) which is a behavioral therapy that incorporates acceptance and mindfulness strategies for behavioral changes used in depression and anxiety which is a known comorbidity with migraine.

**Understanding treatment options.** Many of the studies incorporated migraine medication and non-pharmacological treatments into the intervention in various ways but none of the information was well defined (Cady et al., 2007; Dindo et al., 2012; Matchar et al., 2008; Rothrock et al., 2006; Smith et al., 2010). The Rothrock et al. (2006), Bromberg et al. (2012), and Dindo et al. (2012) studies provided information regarding medication overuse headaches

and how to prevent them by using proper medication management. The Rothrock et al. (2006) study had the only intervention that provided instructions for injection training for migraine abortive medications. Matchar et al. (2008) was the only research in which the headache clinic manager helped each patient to fill out a one page worksheet that itemized their headache type and treatment plan. The next section reviews patient education outcome measures.

### **Measuring Patient Education Outcomes**

All of the studies that were reviewed had positive primary outcome measures in both migraine disability and migraine management related to the PE interventions. Bromberg et al. (2012) could not evaluate its primary outcome measure of migraine disability due to data management error. There were multiple other dependent variables studied, including depression and anxiety which are known comorbidities of migraine, quality of life, patient satisfaction with care, compliance, and measures of locus of control and self-efficacy.

**Disability outcomes.** Eight of the nine studies reviewed used specific migraine disability tools to measure PE outcomes. Five of the studies used an easy to administer seven item Migraine Disability Assessment (MIDAS) measurement questionnaire which is well known for its reliability and validity in evaluating migraine disability (Bromberg et al., 2012; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006). This instrument evaluates migraine disability within a three month period of time. All studies using this method showed statistically significant positive findings including:  $p < 0.001$  (Hu et al., 2004),  $p = .008$  (Matchar et al., 2008), and  $p < .05$  (Nicholson et al., 2005; and Rothrock et al., 2006). The Hu et al. (2004) study, however, also noted the control group value  $p = 0.054$ , was close to a level of significance. Bromberg et al. (2012) lost the MIDAS data.

The Smith et al. (2010) study, using the Headache Impact Test (HIT-6), another well-known six-item measurement of migraine disability with proven reliability and validity, had results of  $p < .01$ . This tool measures migraine disability over a one month period of time. Dindo et al. (2012) used the Headache Disability Inventory (HDI) without known reliability or validity to measure study outcomes and showed findings of  $p = .006$ .

**Management outcomes.** There were three studies that focused on migraine management outcomes related to the study interventions. Cady et al. (2007) used a randomized control trial (RCT) with a pre and post design and a migraine management questionnaire without noting its validity and reliability with results of  $p < .001$ . The Hu et al. (2004) and Campinha-Bacote et al. (2005) studies used the Migraine Therapy Assessment Questionnaire (MTAQ) which had documented reliability and validity. It is a simple nine question survey with dichotomous scales which identify migraine management risk factors. The Campinha-Bacote et al. (2005) study scored each section of the MTAQ separately and did not give a total score so it could not be compared to the Hu et al. (2004) study.

### **Headache National Guidelines**

A search was conducted to find a national guideline that was most suitable for the clinical questions in order to develop a migraine PE program that would provide the knowledge and skills necessary for patients to self-manage their migraine. Using the National Guidelines Clearinghouse database with the search term migraine, there was only one migraine treatment guideline found from the United States which was from the Institute for Clinical Systems Improvement (ICSI). This guideline, called the *Diagnosis and Treatment of Headache*, was also the most up to date standard, having been revised in January, 2013 (Beithon et al., 2013).

The ICSI headache guideline provides comprehensive migraine management recommendations and describes PE of “paramount” importance in controlling headache. They endorse initiation of PE shortly after the diagnosis of migraine is made. There was a strong recommendation for keeping migraine diaries to clarify frequency and severity, migraine triggers, and treatment responses. Other PE recommendations included understanding migraine and genetic predisposition, food and environmental triggers, lifestyle changes related to diet, sleep, stress reduction, and regular aerobic exercise. They stressed the importance of limiting abortive migraine medication to avoid medication overuse headaches. Individualized headache treatment plans were also endorsed.

The American Academy of Neurology (AAN), as a highly respected and influential institution, published preliminary quality measures related to the management of migraine headaches in the fall of 2013; however, the final version will not be published until sometime in the summer of 2014 (American Academy of Neurology [AAN], 2013). These measures also recommended the use of a headache management plan for migraine which includes goals, medications and nonpharmalogical treatments as well as migraine trigger avoidance. Similar to the ICSI headache guideline, the measures also emphasized the importance of PE. Both the ICSI headache guidelines and the AAN headache quality measures recommend the use of migraine disability outcome measures to evaluate migraine management effectiveness.

### **Systematic Review**

A thorough search of the literature was conducted for systematic review articles that would provide insight to the clinical questions. There was minimal yield in this area with only one article found which was an integrative review targeting the pediatric population. This review



written by Craddock and Ray (2012) was deemed appropriate as migraine has the same basic pathophysiology in all people and most ages require very similar PE.

There was limited research in the area of migraine patient education and the intent of the authors was to provide evidence of positive trials related to migraine management that could be used in clinical practice. The review was written from a nursing perspective and recommended a multidisciplinary approach to migraine PE, obtaining input from the patient, the family, and the provider. The analysis concluded that migraine is an incurable disease with complex management issues necessitating an individualized plan of care that can be used as a comprehensive reference tool to assist in controlling migraine attacks and improving quality of life. Prominent PE topics included understanding the diagnosis, medications (including avoidance of medication overuse headache), lifestyle changes such as diet, sleep and exercise, and following migraine triggers and headache incidence with a diary. Craddock and Ray (2012) stressed the importance of addressing migraine comorbidities of depression and anxiety if needed by using relaxation techniques such as biofeedback and breathing exercises. The major strength of this review was its applicability and congruence with the ICSI headache guideline and AAN headache quality measures. The weakness of the review was that there was no statistical analysis leading to issues of validity and reliability.

### **Ranking the Evidence**

In an effort to provide an understanding of the strength of evidence relating to the clinical questions, the 2011 Oxford Centre for Evidence-Based Medicine (CEBM) Levels of Evidence (LOE) document was used to evaluate the research studies based on a ranking scale I-V, with I being the highest level of evidence (see Appendix B).

Based on these rankings, the following studies provided the highest level of evidence (LOE) based on RCT design and sample size at a level of II (see Appendix C): Rothrock et al. (2006) study, Cady et al. (2007), and Matchar et al. (2008). Although the Bromberg et al. (2012) study was a RCT, the migraine disability data was lost and they could only evaluate depression outcomes. The question of quality and imprecision reduced the ranking to a level III. Dindo et al. (2012) study was also RCT; however, the sample population was very small and thus, the study was ranked a level III. The other concern regarding this study was that it provided an intervention for both migraine and depression comorbidities. The other migraine PE studies, which were quasi-experiment designs were ranked at a level III (Campinha-Bacote et al., 2005; Hu et al., 2004; Smith et al., 2010) except for the Nicholson et al. (2005) whose study was downgraded to a level IV due to small sample size. The integrative review from Craddock and Ray (2012) was rated at a level IV, due to no statistical analysis, leading to significant issues with validity and reliability, although its strength was the themed recommendations which were found to be consistent with the ICSI headache guideline and the AAN headache quality measures.

### **Integrative Review**

The purpose of this study was to understand the perspectives of migraine patients and neurology providers at a Midwestern neurology clinic regarding migraine PE. Furthermore, this study sought to develop a migraine PE program that would provide the knowledge and skills necessary for patients to independently manage their migraine. A thorough review of the literature using multiple sources was analyzed, synthesized, and summarized.

These studies supported the need for migraine PE with the specific content to include information on diagnosis, trigger factors, medications, and lifestyle such as sleep, diet, exercise,

and stress. Migraine diaries were recommended to capture data regarding migraine status and triggers (AAN, 2013; Beithon et al., 2013; Bromberg et al., 2012; Campinha-Bacote et al., 2005; Craddock & Ray, 2012; Dindo et al., 2012; Hu et al., 2004; Matchar et al., 2008; Nicholson et al., 2005; Rothrock et al., 2006; Smith et al., 2010).

The evidence emerging from the literature indicated that a variety of PE methods improved patient outcomes. It was, nevertheless, difficult to generalize the results of the nine original migraine studies due to the fact that study participants were not demographically defined in regard to literacy levels and there was no mention of minority groups. The majority of studies (Bromberg et al., 2012; Campinha-Bacote et al., 2005; Hu et al., 2004; Nicholson et al., 2005; Smith et al., 2010) involved written PE materials at undefined reading levels and the PE interventions had little or no human contact. This situation was a major concern because only 12% of people in the United States have proficient health literacy (U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion, n.d.). Furthermore, in the Nicholson et al. (2005) study, illiterate individuals were excluded from the study and the Bromberg et al. (2012) study excluded non-English speaking individuals. This exclusion created critical validity issues and thus, the results cannot be applied universally to all cultures and health literacy levels. These concerns are of clinical significance because of the disabling nature of migraine and the knowledge gap pertaining to those who may not be receiving the knowledge and skills necessary to self-manage their migraine, particularly individuals with low reading levels, language barriers, or cultural differences. This knowledge gap could heighten health care disparities and patient dissatisfaction.

The Matchar et al. (2008) study had the strongest research evidence for a patient-centered model, which included patient stakeholder involvement with a PE program offering

individualized and group PE programs with personalized plans of care. This framework was echoed in the findings of Craddock and Ray (2012) and the ICSI headache guideline (Beithon, 2013) as well as the AAN headache quality measures (2013).

Measuring disability using a valid and reliable migraine disability tool such as the MIDAS or the HIT-6 is needed to evaluate PE outcome measures to determine whether the PE activities are successful and migraine management is suitable for all individuals.

### **Summary of Literature Review Recommendations**

Migraine is a common condition seen in primary care and neurology clinics which can significantly impact lives. This ailment requires a sizeable amount of PE in order for people to take control of migraine and reduce disability. This can be difficult to achieve as clinics are often very busy and lack the time and resources to educate patients. Most clinics use written PE materials which are easiest to provide. This is a significant concern because PE should be more than just providing patients with volumes of written information to obtain the knowledge and skills needed to manage their migraine. PE reading materials often have dense and technical language. Fear and embarrassment are likely to hinder many people from asking questions or seeking clarification. Moreover, cultural and language barriers as well as low literacy levels exacerbate the problem of effective communication. In short, written PE materials may be appropriate for some as noted by the positive outcomes in the original research; however, they are not suitable for all populations.

Group PE for migraine may not be appropriate for a number of individuals of diverse cultures and educational levels. Non-professional migraineurs educating other migraine patients pose a major concern as they do not have the necessary training. Using videos may be a helpful adjunct to educate patients with migraine, however, in the Cady et al. (2007) study, it was the

nurse's PE reinforcement that made a statistically significant difference in the outcomes, arguing that the human interaction component is an important part of PE.

In summary, the literature clearly defined the content of what people with migraine need to know to manage migraine; nonetheless, the question left to answer was what method would be best to educate migraine patients to ensure that individuals of all reading levels, languages, and cultures would be provided the knowledge and skills to independently manage their migraine. Although studies that excluded people who were illiterate and non-English speaking guaranteed better outcomes, the question that remained was how do we educate these populations and the people with less than proficient health literacy, a number estimated to be 88% in America?

This systems change project could provide further insight into methods of migraine PE that would ensure all patients have appropriate PE to promote self-care in living with migraine. All of the evidence reviewed and analyzed laid a solid foundation for migraine education and provided the strength and support for further research.

### **Chapter 3**

#### **Methodology**

The purpose of this study was to understand the perspectives of migraine patients and neurology providers at a Midwestern neurology clinic regarding migraine PE. Furthermore, this study sought to develop a migraine PE program that would provide the knowledge and skills necessary for patients to self-manage their migraine. There were two clinical questions related to this systems change project. The first question posed was: In a Midwestern neurology clinic, do the current methods of PE provide the knowledge and skills necessary for patients to self-manage their migraine? The second question was: In a Midwestern neurology clinic, does a patient-centered and evidenced-based PE migraine management plan provide the knowledge and skills necessary for patients to self-manage their migraine?

#### **Systems Change Project Setting and Site Support**

The setting of this systems change project was a large physician-owned Midwestern neurology clinic with six locations. The clinic's mission is to provide high quality neurology services for a wide variety of neurological conditions which are thorough, considerate, and cost-effective. Clinic culture is consistent with this mission. There is a high level of employee stability, loyalty, mutual trust, and commitment within the organization.

The neurology clinic, like most other health institutions, has always used the traditional disease-centered model of PE consisting of written PE materials for the care of migraine headache patients. Although written materials are by far the most frequently used tools for educating migraine patients, they may be unsuitable for a number of patients who cannot read or comprehend the materials. Using a patient-centered approach would provide more individualized migraine education and promote patient responsibility. This systems change project is congruent

with the clinic's mission and culture. The organization is supportive, motivated, and enthusiastic about this major undertaking as well as very willing to participate in the process which shows their dedication to clinic patients and commitment to high quality care and value.

### **Design**

This systems change project utilized a quality improvement design using a qualitative descriptive approach involving two phases. Phase I was a cross-sectional survey design used to solicit information and opinions regarding the current methods of PE from the stakeholders— the neurology providers and migraine patients. Phase II involved a pilot study implementing and evaluating the migraine PE management plan intervention which was created from Phase I stakeholder input, extensive literature review, as well as the evidence-based headache guideline from the Institute for Clinical Systems Improvement (ICSI) and the quality measures from the American Academy of Neurology (AAN).

### **Sample**

The population for Phase I of this project was comprised of 35 neurology clinic providers including neurologists, nurse practitioners, and physician assistants. There were also 200 neurology clinic patients, aged 18 and above, with a diagnosis of migraine headaches. In Phase II of the study, there were five neurology providers and 25 patients, aged 18 and above, with a diagnosis of common or classical migraine headaches.

### **Ethical Considerations**

Both phases of the project were approved by the Institutional Review Board (IRB) at St. Catherine University. In keeping with the IRB requirements, each potential participant was provided with an informed consent (see Appendices D-G). Participants were told that the

research study was voluntary and they were free to discontinue participation at any time and it would not affect their relationship with the neurology clinic or St. Catherine University.

### **Phase I: Needs Assessment**

Phase I of this project used survey methods to gain insight into the current methods and subject matter used for migraine PE at the Midwestern neurology clinic to determine if change was needed. An IRB approved emailed survey was created for neurology providers and sent via Survey Monkey internet services (see Appendix H). The inquiry form also included questions related to how much time was needed for the migraine PE process, and in particular, how patients of cultural, educational, and socioeconomic diversity were educated. Neurology providers were specifically asked if they would be supportive of changes in migraine PE at the clinic to promote self-management for all migraine populations. A second IRB approved survey was developed and mailed to current adult migraine patients at the clinic to elicit information regarding their current PE experiences and changes that could be made to enhance their learning ability to be self-reliant and more satisfied in living with their migraine (see Appendix I).

Data from both provider and migraine patient surveys were collected and summarized using Survey Monkey internet services. The project manager analyzed the data and common themes were identified. Details of this analysis will be found in Chapter Four.

### **Phase II: Project Approval**

In approving Phase II, recommendations were proposed at the August 2013 Midwestern neurology clinic executive board meeting. It was universally agreed upon that the migraine PE project must be congruent with both the ICSI headache guideline and the preliminary AAN headache quality measures. Key migraine PE points that were favored by stakeholders in Phase I included:



- 1) PE should take place at regularly scheduled office visits by the migraine patient's neurology provider.
- 2) Individualized migraine plan of care that would outline the patient's treatment should be provided for the patient to take home.
- 3) PE materials that would be easy to understand for all individuals should be provided.
- 4) PE information that includes recognizing migraine symptoms, how to prevent migraine by avoiding migraine triggers, use of a headache diary, how to manage migraine at home, and understanding medication and non-medication treatments should be provided.
- 5) The principles of health equity should be embedded in all migraine PE methods to ensure proper education to all diverse populations.

### **The Headache Management Plan**

The Headache management plan (HMP) is the researcher designed PE intervention tool created from the stakeholder surveys from Phase I of the systems change project with input from the literature review and the evidence-based ICSI headache guideline and the AAN headache quality measures (see Appendix J). The HMP is designed specifically for patients with a diagnosis of migraine. It is a written plan of care that is made at the time of the appointment in collaboration with their neurology providers. Together they evaluate headache status based on headache assessment tools, as well as the type and amount of abortive medications used. Based on these measurements, the patient would be classified as having good headache control, fair headache control, or poor headache control. The ultimate goal is to maintain good headache control. Discussion would then ensue regarding abortive, preventative, and rescue medications for their specific type of headache if needed. This interaction also promotes specific discussion regarding nonpharmacological therapies and customized patient education information.

Providing every adult migraine patient with an individualized plan of care to take home and use is a patient-centered strategy that will offer patients a sense of empowerment. The plan fosters better communication, accuracy and outcomes, thereby increasing patient safety at all education, cultural, and socioeconomic levels. This intervention was the first of its kind in the neurology clinic and was a major conceptual change in the way the providers practice.

### **Evaluation of the Headache Management Plan**

The HMP was the researcher's first attempt towards developing a patient-centered and evidence-based PE tool with stakeholder input. The Phase I needs assessment clearly identified that both migraine patients and neurology providers wanted a migraine action plan. Using a patient-centered framework for the HMP ensured that all individuals' preferences, needs, and values were taken into consideration. The next segment provides a rationale and evaluation of the HMP form, along with explanation of each document section.

#### **Headache Management Plan: The Format**

The HMP form needed to be consistent, efficient, as well as simplified and goal focused in a one page document for migraine patients to take home to independently manage their migraine. Trying to provide the most useful and succinct information on a one page document was a long and laborious task. In order to keep the plan to one page as other exemplar migraine action plans did, and to provide as much essential information as possible, the typical font size of 12 was compromised to a size 9. Document font size was reduced from 9 to 7 in the appendix to allow for proper formatting (see Appendix J).

Furthermore, the language use in the HMP raises questions. Some words in the HMP were not fully explained as there was not enough room for full explanations; it would have been good to explain that nitrates which are a prominent migraine trigger, are chemicals found in

foods such as lunch meat and hotdogs. Despite this, there were no migraine patient or neurology provider participants who mentioned language difficulty in the survey.

Secondly, readability of the HMP could not be determined. There were two reasons for this. The SMOG readability calculator score (NIACE, n.d.) could not be used because the document needed to be in narrative form to allow at least 10 sentences in a row to be evaluated. In addition, the SMOG readability calculator would have been inaccurate as in order to allow patients to be familiar with some of the most frequently used migraine terminology that the provider may use, complicated medical terms such as “preventative medication,” were defined in parentheses as “to prevent headaches from coming.”

### **Headache Management Plan: The Content**

Although there was suggested information for inclusion of a migraine action plan in the ICSI headache guidelines and the AAN Quality Measures, few models of migraine action plans were found in the literature (The Permanente Medical Group, 2007; Community Health Plan, 2011; Fairview, 2012). The researcher decided to call the migraine PE tool the Headache Management Plan (HMP) as many people have more than one headache type. Each of the four sections of the HMP will be discussed below.

**My Diagnosis.** The first section of the HMP is dedicated to the specific headache diagnosis. Many migraine patients often have more than one headache diagnosis and these can change over time. According to Bigal, Krymchantowski, and Lipton (2009) nearly half of migraineurs who seek medical care in a given year are unaware of their migraine diagnosis. Thus, it is essential to provide and discuss headache diagnosis at each appointment.

**How am I doing?** Providing detailed facts about the patients’ migraine status, such as their Headache Impact Test score, number of emergency or urgent care visits, and number of

headache days per month is extremely valuable information in the migraine evaluation process as well as in heightening the patients' awareness of the severity of their condition in order to help them set their goals.

In addition, knowing the number of days per month of prescribed or over the counter medication to abort headache is essential in the prevention of medication overuse headaches, also commonly known as rebound headaches. It is estimated "that more than 50% of the patients seen at headache clinics meet the criteria for medication overuse headache" (AAN, 2013, p. 54). Since these types of headache are frequently seen in migraine patients and can be a significant cause of disability, recognizing these relentless headaches is important as the treatments are different than for migraine. If migraine patients are found to be overmedicating, there is a special section under the "my headache management," to write an individualized abortive medication reduction plan to work on until the next patient-provider encounter.

**My headache management.** The treatment management portion of the HMP has the migraine patients' individualized plan of care, including abortive and preventative medications, rescue plan for migraine, as well as non-drug treatments. Writing a plan of care in collaboration with the neurology provider allows patients to be actively involved in their care and helps them to remember their treatments. The HMP not only helps migraine patients to remember their treatments, but it is also a checklist for neurology providers to ensure that all migraine treatments and migraine PE is consistently addressed at each appointment.

**Patient Education.** The intent of the patient education portion of the HMP was to provide patients with migraine specific information including topics such as the initial signs of a migraine, since studies indicate that migraineurs who treat migraine pain early with abortive medication reduced pain recurrence (Goadsby, 2008). The PE section also includes identification

of migraine trigger factors as studies have shown that up to 91% of migraine patients report at least one migraine trigger producing migraine (Andress-Rothrock, King, & Rothrock, 2010). Identifying and avoiding these migraine attack triggers could potentially reduce migraine frequency. The HMP also provides patients with important information regarding what can be done if a migraine occurs, what can be done to manage migraine day-to-day, and when to call the neurology provider.

Prior to Phase II implementation, there was a HMP peer review from several neurology providers at the clinic, predominantly nurse practitioners and physician assistants who most commonly perform PE activities at the neurology clinic. Based on their input the plan was revised.

### **Cost Benefit Analysis of the Headache Management Plan**

The application of economic principles is essential to ensure successful implementation of a systems change innovation. It is important to quantify the cost of resources and the return on investment (ROI) of the project (Alkin, 2011).

**Resources.** Identifying resources to achieve the goals is one of the first steps in initiating the systems change project. In Phase I and II of the project, paper supplies and stamps for the patient surveys were donated by the neurology clinic. The researcher purchased a membership to Survey Monkey internet services for data gathering purposes and statistical analysis for \$300.00 which was an in-kind donation. The major expense of the study was time invested by the five neurology providers in Phase II totaling approximately 4 hours to the project. Salary for the neurology physicians was taken from the *Neurology Compensation Report 2013* (Medscape, 2014). Salary for the physician assistants was taken from the *Advanced Healthcare Network for NPs & PAs* (Wolfgang, 2014). The vast majority of the project time involved the project

manager which was an in kind-donation. The total cost of the systems change project was estimated at \$365 (see Appendix K). The price of the program is minimal when compared to the perceived benefits to migraine patients.

**Return on Investment (ROI).** One of the major cost advantages of the HMP is related to emergency room (ER) costs avoided. According to Friedman, Serrano, Reed, Diamond, & Lipton (2009), seven percent of Americans with migraine reported using the ER for treatment within the previous 12 months. Insinga et al. (2011) noted in their research that the national average cost of an ER visit was approximately \$775. Using a conservative estimate of reducing ER visits by 10% with improved migraine management in the approximately 5,050 migraine patients that were seen at the neurology clinic from October of 2012 to October 2013, it could produce a cost savings of \$27,396.25. By dividing this sum by 1.05, it would provide the present value in one year from the start of the program— \$26,091.67.

However, the biggest cost benefit would be related to lost earnings avoided. On an average, there are 8 days of lost work per year due to migraine (Hazard, et al., 2009). There were approximately 3,600 work-force aged (16-65) migraine patients seen from October of 2012 to October of 2013 in the neurology clinic. The lost earnings avoided estimate is produced by first removing those people who would not likely be working by multiplying the county force participation rate in Hennepin County of 68% (“Labor force of Hennepin County, MN,” n.d.) which makes 2,448 migraine working individuals. According to the U.S. Department of Labor, Bureau of Labor Statistics (n.d.), the Hennepin County specific average weekly wage is \$1,133 (divided by five to get a daily wage of \$226.60). If this number is multiplied by those working (2,448) it will equate to \$4,438,224.00, which is the total possible lost earnings per year. If there were a modest 10% reduction in lost earnings related to better migraine management, this would

produce a cost savings of \$443,822.4. By dividing this sum by 1.05, it would provide present value in one year from the start of the program— \$422,688.00.

The ROI was calculated using the formula:  $(\text{total benefits} - \text{total costs}) / \text{total costs} \times 100$ . Therefore,  $\$448,779.67 - \$365 / \$448,779.67 \times 100$  yielded an estimated  $99.92 = 100\%$  ROI related to the migraine management plan in the neurology clinic.

The improved outcomes, quality improvement, and value could be rewarded by insurance companies adding the clinic into preferred networks. Much of the return on investment will be related to improved patient satisfaction and quality of life associated with better migraine control. Better treatment adherence would improve safety, as well as lower the incidence of medication overuse headaches, and long-term complications of chronic migraine. Initiating the HMP could also potentially reduce the number of headache related phone calls and unscheduled visits at the clinic over time. This reduction would in turn reduce staff stress levels and provide clinic staff with better job satisfaction.

### **Pilot Study**

The HMP is a written summary of the migraine related appointment which includes PE information to help patients gain the knowledge and skills needed to self-manage their migraine. It is a form which is completed by the neurology provider (neurologists, nurse practitioners, and physician assistants) and migraine patient collaboratively at a routine migraine appointment.

The HMP was evaluated by performing a pilot study. This trial was a descriptive cross-sectional design with the purpose of implementing and evaluating the use of a migraine management plan for adult migraine patients in a neurology clinic. The pilot study began with recruitment of five neurology providers to participate in the pilot study using the HMP on five of their adult migraine patients at regularly scheduled appointments. The researcher set up 30

minute individualized educational meetings with each recruited neurology provider to review study protocols and provide guidance before migraine patient recruitment was started.

Migraine patient study participants had inclusion criteria of being age 18 and above with a diagnosis of common or classical migraine. Individuals were recruited using informed consent. If the patient agreed to be in the study, then the neurology provider and the patient would use the HMP collaboratively at the appointment and the migraine patient would take the plan home to help self-manage their migraine. At the migraine patient's next follow-up appointment with the neurology provider, which was approximately 4-6 weeks afterward, there would be a routine evaluation of migraine status and another migraine management plan would be collaboratively completed.

Immediately following the second appointment, both the neurology provider and the migraine patient filled out a brief survey regarding utilization of the migraine management plan (see Appendix L). The neurology providers completed a survey for all five of their migraine headache patient participants in the pilot study (see Appendix M). If the patient did not want to participate in the study, then usual migraine care by the provider was given without the migraine management plan. The timeline for the systems change project is laid out below.

### **Project Timeline**

- 4/24/13 – IRB approval for Phase I: PE stakeholder needs assessment surveys
- 6/1/2013 – 7/1/2013 – Phase I PE needs assessment survey data collection
- 8/15/2013 – Meeting with clinic executive board for Phase I needs assessment survey data results summary and Phase II Project Approval
- 8/16/13 – 12/10/13 – Development of the HMP
- 1/22/14 – IRB approval for Phase II: Implementation and evaluation of the HMP
- 1/23/2014 – Initiation of Phase II: Implementation and evaluation of the HMP pilot study



- 2/28/2014 – 4/14/2014 – Phase II data collection from the HMP stakeholders' surveys
- 5/2014 – Dissemination of results

In the next chapter, details of Phases I and II results will be provided and to conclude, Chapter Five will discuss the major findings and offer recommendations.

## **Chapter 4**

### **Results**

The purpose of this study was to understand the perspectives of migraine patients and neurology providers at a Midwestern neurology clinic regarding migraine PE. Furthermore, this study sought to develop a migraine PE program that would provide the knowledge and skills necessary for patients to independently manage their migraine.

This project was completed in two phases. Phase I used survey tools to gain understanding about migraine PE from neurology providers and migraine patients. Phase II of the project created, implemented, and evaluated a PE tool called the HMP with a pilot study.

#### **Phase I Results**

Descriptive qualitative methodology was used in the form of neurology providers and migraine patient surveys to gain insight to what the current migraine PE practices were and whether changes needed to be made to improve them. There were 200 migraine patient education surveys mailed out to patients age 18 and above who had been patients at the Clinic within a six to 12 month time period. Migraine patient response rate was 18%. One possible reason for this could have been related to the frequency of other types of patient surveys which were typically given after every clinic office visit or procedure. Migraine patients were called in follow up approximately 10 days after the surveys were sent. Out of those that the project manager called and personally spoke to, almost all had reported immediately throwing the surveys away. Some of them requested a second survey to be mailed. Most patients had voice mail and messages were left regarding the survey. Only one patient called back to request another survey noting that she had thrown her original survey away, not realizing that it was for a migraine quality improvement initiative. The neurology provider migraine survey response rate was a robust 80%

via the emailed survey with three email reminders. This strong response was viewed by the researcher as being indicative of their support of the project.

There were two separate migraine PE surveys sent out to adult migraine patients and neurology providers (Appendices H & I). Of the survey questionnaires, there were three questions that were specifically designed for migraine patients. There were seven questions specifically designed for neurology providers, and there were four questions that were addressed to both groups.

### **Demographics**

The mean age of the migraine survey participants was 40 years old and the vast majority of them were female at 97%. This is consistent with the US migraine prevalence rates with women being three times more likely than men to have migraine (Lipton, 2001). Mean years of schooling was 15. All participants had a minimum of 12 years of schooling and all spoke English as a primary language. Patients of lower education levels and non-English speaking patients were not represented. This may have been related to the lack of understanding the consent form and survey. Demographics of the neurology provider participants included 29 neurologists, two nurse practitioners, and four physician assistants. There were 17 female providers and 18 male providers participating in all.

### **Migraine Patient Specific Patient Education Survey Questions**

The first survey question that was directed specifically to migraine patients (Table 1) asked the following question, “How would you rate your overall migraine patient education experience at the clinic?” The majority of respondents rated their migraine PE experience as good, very good, or excellent with the mean response of good at 13%.

Table 1

*Rating of Migraine Patient Education Experience*

Poor	Fair	Good	Very Good	Excellent
8% (3)	16% (6)	36% (13)	20% (7)	20% (7)

The second migraine patient survey question (Table 2) asked the query, “How confident are you in managing your migraine headaches at home?” It was noted that younger migraineurs were less confident, particularly those who rated their migraine experience as poor, fair, or good. There was a trend of older (more experienced) migraineurs who felt more confident in managing their migraine at home, even if they rated their migraine education less favorable.

Table 2

*Level of Confidence of Managing Migraine at Home*

Not at All Confident	Slightly Confident	Somewhat Confident	Very Confident	Extremely Confident
6% (2)	20% (7)	22% (8)	33% (12)	19% (7)

The third question directed to migraine patients asked an open ended question to provoke exploration of the topic in the patient’s own words. This question probed, “What could we do at the clinic to make your migraine education experience better?” There were 18 comments in all and the majority (11) was a reiteration of what they felt they needed to know in order to manage migraine. Two people commented on the methods of migraine PE, with one wanting individualized teaching and the other wanting group PE as well as a support group. Two patients expressed the wish to be seen more frequently or to have more time spent on migraine education.

Three individuals described their migraine PE as “poor” and “ineffective,” while the other individual said, “TEACH ME! You did nothing in the way of education.”

**Migraine Provider Specific Patient Education Survey Questions**

The first survey question that was directed specifically to neurology providers (Table 3) asked the following question, “Do you use the same patient education information for all adult migraine headache patients, including populations of cultural, educational, and socioeconomic diversity?” In the neurology provider surveys, 64% used the same PE materials for all migraine patients regardless of race, ethnicity, and educational level. Of those that did provide different migraine PE information, there was not a formalized procedure for plan of care.

Table 3

*Percentage of Neurology Providers Using the Same Patient Education Information for All Adult Migraine Headache Patients, Including Populations of Culture, Education, and Socioeconomic Diversity*

Yes	No
64% (18)	36% (10)

The second neurology provider question was connected to the first, asking the probing question, “If you do not use the same patient education information for all adult migraine patients, how do you educate these diverse populations?” This exploratory question was used to find out what resources neurology providers were using for migraine PE in diverse populations. One provider mentioned the use of tailored verbal communication but without explanation of what that entailed. One provider used pictures to provide better understanding of migraine, while another one used an “individualized plan of care based on the patients’ needs.” Many providers mentioned the use of a translator to assist with the PE interaction. One provider noted the

challenge of non-English speaking patients and their need for more basic information regarding their medications. For example, they need to know and understand how to obtain medication, how to obtain refills, not to stop medication when they feel better or if they run out of medication, and to call if experiencing side effects.

The fourth question posed to the neurology providers was directed to the amount of time that they felt was needed to provide migraine PE (Table 4): “In your opinion, what would be the average amount of time needed to provide patients with the knowledge and skills to manage migraine?”

Table 4

*Time Needed to Provide Migraine Patients the Knowledge and Skills to Manage Migraine*

5-10 Minutes	11-15 Minutes	16-30 Minutes	31-45 Minutes	46-60 Minutes
4% (1)	4% (1)	46% (12)	35% (9)	11% (3)

Although 16-30 minutes was the number one response at 46%, 31-45 minutes and 46-60 minutes together also equals 46%. Three providers commented on need for follow up appointments for continued education—not just one session but a continuous education process noting that patients need repetition in order to remember the migraine information provided.

The fifth neurology provider question focused further on the topic of time in the context of PE (Table 5). The specific question asked, “Do you feel that you have enough time in your schedule to adequately educate your migraine patients?”

Table 5

*Neurology Providers’ Perceptions of Adequate Time Available to Educate Migraine Patients*

Never	Rarely	Sometimes	Often	Always
0% (0)	29% (8)	28% (8)	39% (11)	4% (1)

There were only four percent of providers (one person) who felt that they always had enough time to educate their patients while the most common response of 39% was often had enough time. The responses indicated that time may be a major factor in providing adequate migraine PE. Migraine patient educational needs and the time it takes to educate vary depending on their patient’s migraine experience, language, culture, and health literacy level.

The sixth provider question (Table 6) in the survey inquired specifically about their perceptions of whether their migraine patients were getting adequate PE: “Do you feel that your migraine patients are getting the education and skills necessary to manage their migraine?”

Table 6

*Neurology Providers’ Perceptions of Their Patients Receiving Adequate Education and Skills Needed to Manage Their Migraine*

Never	Rarely	Sometimes	Often	Always
0% (0)	3% (1)	36% (10)	54% (15)	7% (2)

Of the providers who responded, only seven percent (two providers) felt that their migraine patients were always getting the knowledge and skills needed to manage their migraine while just over 50% felt that patients were often getting the education needed to manage

migraine. Patients are not consistently getting the migraine education and skills needed to manage their migraine.

The last neurology provider specific question posed (Table 7) was, “Would you be supportive of changes in the adult patient migraine education at the clinic?”

Table 7

*Neurology Provider Support for Changes in Adult Migraine Patient Education at the Clinic*

Strongly in Favor	Somewhat in Favor	Neutral	Somewhat Opposed	Strongly Opposed
44% (12)	41% (11)	11% (3)	4% (1)	0% (0)

The clinic providers overwhelmingly were in favor of changes in adult migraine PE at the clinic with 44% strongly in favor and 41% somewhat in favor. No one was strongly opposed.

Just like the migraine patient survey, there was an open ended question for further comments regarding neurology provider opinions concerning migraine PE. Simply stated, “Please add any additional comments you have regarding adult migraine patient education at the clinic.” This was an unrestricted question to elicit any further comments about migraine PE that had not been addressed in other sections of the provider survey. There were six provider responses. One person noted “Everyone is different. Not all treatment modalities work for all patients and thus, generalized information is not as useful as individually tailored plans.”

Another individual said, “The most important part of migraine education is for the individual to understand their own migraine disorder and learn how to manage this disorder and treat episodes aggressively. My job is to give them the tools to do this.” Others commented on the usefulness of headache diaries to provide feedback and the need for migraine information geared toward diverse populations. Another provider mentioned the need to empower the migraine patient. This



comment was likely related to the need of migraine patients to take responsibility to manage their migraine.

**Survey Questions Addressed to Both Migraine Patients and Providers**

The first survey question targeted to both migraine patients and neurology providers focused on the type of migraine PE received. This query was intended to compare perceptions of both groups regarding PE (Table 8). The specific question asked was, “What type of education did you receive (do you provide) for migraine headaches?” There could be more than one response.

Table 8

*Type of Migraine Patient Education Received (Provided)*

Migraine PE received	Migraine Patients	Neurology Providers
Discussion about migraine education at an office visit	81% (29)	100% (28)
Migraine information from a website	11% (4)	21% (6)
The Minnesota Headache Center Folder	14% (5)	43% (12)
No migraine patient education	8% (3)	0% (0)
Other	17% (6) – gave other responses of searching the internet for information on their own	7% (2) – gave other responses of providing illustrations of migraine and mailed clinic notes with PE instructions

According to the surveys, the most common type of migraine PE was verbal information given at an office visit. Up to 43% of neurology providers used the Minnesota Headache Center

folders with educational materials noted to be at a grade 14 reading level and in desperate need of updating. This could create health care disparities in people with low health literacy. Many of the neurology providers gave patients migraine educational information from a website and many patients noted that they searched the internet on their own to learn more about migraine management. There was eight percent of patients that had believed they had no migraine PE whatsoever which either indicated that minimal PE had occurred or the patient wasn't aware that the verbal exchange at the office visit was indeed migraine PE.

The second combined survey question asked was, "What are the most important things to know in order to manage migraine?" Responses were in order of their priority with the average ranking noted in parentheses (Table 9).

Table 9

*Most Important Things to Know to Manage Migraine*

Migraine PE Content Priorities	Migraine Patients	Neurology Providers
Understanding how to prevent migraine by avoiding triggers	1 (4.40)	3 (3.54)
Learning how to make an action plan to treat migraine	2 (4.00)	2 (4.79)
Understanding migraine and related symptoms	3 (3.89)	1 (4.96)
Understanding migraine medications	4 (3.26)	4 (3.54)
Learning about migraine diet and lifestyle changes	5 (2.83)	5 (2.43)
Learning about non-medication treatments	6 (2.63)	6 (1.75)

The migraine PE content priorities were different between the migraine patients and neurology providers, in that the migraine patient’s number one priority was to learn how to prevent migraine by avoiding migraine triggers, whereas for neurology providers, understanding migraine and its related symptoms was compellingly the top priority. The second priority of both the migraine patients and neurology providers was to have a migraine action plan in order to know how to manage migraine at home.

The last question aimed at both migraine patients and neurology providers was linked to the previous question and asked, “What would be the best way to learn the information needed to manage migraine?” Responses were in order of their priority with the average ranking noted in parentheses (Table 10).

Table 10

*Individual Migraine Patient Education Method Priorities*

<b>Individual Migraine PE Method Priorities</b>	<b>Migraine Patients</b>	<b>Neurology Providers</b>
Talking to my provider	1 (5.17)	1 (5.33)
Reading migraine information on own from the clinic	2 (4.17)	3 (3.70)
Reading migraine information on own from recommended websites	3 (3.80)	4 (2.89)
Individual migraine education	4 (2.89)	2 (4.41)
Clinic website presentation	5 (2.51)	5 (2.44)
Group education session for migraine	6 (1.94)	6 (2.22)

Both the migraine patients and the neurology providers overwhelmingly wanted migraine PE delivered through their own providers. The patients' second and third most popular response regarding migraine PE method priorities was reading migraine PE information on their own from the clinic or from recommended websites. Those particular findings correlate with the high educational levels of the migraine patient survey participants. The neurology providers' second choice of migraine PE was individualized sessions.

In summary, migraine patients were not getting adequate and consistent migraine PE. Many were not feeling confident in treating their migraine at home, especially the younger migraineurs who lacked the experience in living with migraine. Time constraints were a major factor in providing patients with sufficient migraine education. Office time for migraine PE could possibly be reduced if migraine patients could collaborate with their own providers to create an individualized action plan which would include basic migraine information such as their migraine triggers, medications, as well as other holistic treatments to manage migraine at home.

As a reminder, the key migraine PE points that were favored by stakeholders in Phase I included:

- 1) PE should take place at regularly scheduled office visits by the migraine patient's neurology provider.
- 2) Individualized migraine plan of care that would outline the patient's treatment should be provided for the patient to take home.
- 3) PE materials that would be easy to understand for all individuals should be provided.

- 4) PE information that includes recognizing migraine symptoms, how to prevent migraine by avoiding migraine triggers, use of a headache diary, how to manage migraine at home, and understanding medication and non-medication treatments should be provided.
- 5) The principles of health equity should be embedded in all migraine PE methods to ensure proper education to all diverse populations.

The Headache management plan (HMP) is the researcher designed PE intervention tool created from the stakeholder surveys from Phase I of the systems change project with input from the literature review and the evidence-based ICSI headache guideline and the AAN Quality Measures (Appendix J).

### **Phase II Results**

Phase II of the systems change project used a descriptive qualitative methodology to evaluate the clarity and effectiveness of the newly created HMP. The main objective of HMP was to provide a consistent and efficient method of migraine PE which would be patient-centered and evidence-based. This plan of care would be completed in collaboration with the patient and neurology provider at the time of a typical migraine related appointment and would include PE information to help patients gain the knowledge and skills needed to manage their migraine independently.

The HMP was evaluated by performing a pilot study which was a descriptive cross-sectional design. The research began with recruitment of five neurology providers to participate in the pilot using the migraine management plan on five of their adult migraine patients at regularly scheduled appointments. The project manager set up 30 minute individualized educational meetings with each recruited neurology provider to review study protocols and provide guidance before migraine patient recruitment was started.

Migraine patient study participants had inclusion criteria of being age 18 and above with a diagnosis of common or classical migraine. Individuals were recruited using informed consent. If the patient agreed to be in the study, then the neurology provider and the patient would use the HMP collaboratively at the appointment and the migraine patient would take the plan home to help self-manage their migraine. At the migraine patient's next follow-up appointment with the neurology provider, which was approximately 4-6 weeks afterward, there would be a routine evaluation of migraine status and another HMP would be collaboratively completed.

Immediately following the second appointment, both the neurology provider and the migraine patient filled out a brief survey regarding utilization of the HMP (see Appendix L). The neurology providers completed a survey for all five of their migraine headache patient participants in the pilot study (see Appendix M). If the patient did not want to participate in the study, then usual migraine care by the provider was given without the HMP. The five post HMP survey questions were the same for both the migraine patients and neurology providers to evaluate the HMP, looking at the perceptions of both migraine patients and neurology providers. Each answer had the word "explain" after it to be able to capture any additional thoughts related to each question.

### **Demographics**

The goal was to reach an enrollment figure of 25 migraine participants. In the seven week enrollment period, there were 21 patients recruited with neurology providers noting some difficulty related to patients not wanting to participate or not meeting the inclusion criteria. Of these 21 participants, only 15 completed the entire study. This was related to a high rate of late cancellations (<24 hours) or failing to attend the follow up appointments at a 21% rate which was higher than the clinic's usual 15%. This low enrollment number was despite clinic phone

calls and follow up letters to the migraine patient participants. Weather was a factor in at least one case. One migraine participant cancelled days before the appointment due to emergent family issues. Another migraine participant’s appointment was cancelled by the provider and rescheduling could not be completed despite many attempts to contact the individual.

The mean age of the migraine patient participants in Phase II was 38 years old and all but one was female. The mean number of years of schooling was 14. One migraine patient participant’s schooling was not known and one had gotten their GED. All but one spoke English as a primary language. The Headache Impact Test, which is one way of evaluating migraine disability at the clinic, average score was 65, indicating that the migraine patient participant’s headaches were causing a very severe impact on their life. It was unknown whether this high severity score could have played a role in reduced appointment attendance. Demographics of neurology providers revealed three neurologists and two Physicians Assistants participants. Four providers were female and one was male.

**Survey Question One**

The first survey question for both the migraine patients and neurology providers in Phase II (see Table 11) of the study asked, “Was the Headache Management Plan easy to understand?” The intent of this question was to detect if there was difficulty in comprehending any parts of the plan.

Table 11

*Ease of Understanding the Headache Management Plan*

	Migraine Patients	Neurology Providers
Yes	100% (15)	100% (15)
No	0% (0)	0% (0)

All of the migraine patients and neurology providers felt that the HMP was easy to read and understand. There were very few explanations and they were mainly from the patients, which included the comments “easy to follow” and “very straightforward.”

**Survey Question Two**

The second question focused on the sense of the patient feeling more actively involved in their migraine care (Table 12), asking, “Did the Headache Management Plan allow you (your patient) to be more actively involved in the planning of your (their) migraine treatment?”

Table 12

*Migraine Patient Increased Active Involvement in Migraine Treatment*

	Migraine Patients	Neurology Providers
Yes	100% (15)	73.33% (11)
No	0% (0)	26% (4)

All of the migraine patients participants felt more actively involved in their migraine care with very positive comments such as “I was able to be a part of the treatment plan,” “I was able to discuss my treatments,” and “I gave feedback about my treatment.” Another migraine patient participant said that the plan made her think more about the trigger factors causing her migraine, another was very happy about seeing a comprehensive plan that provided her with a backup plan for severe migraine. One provider noted that the patient completely forgot about the plan between appointments. Another provider did not feel it helped with her patient interaction as the patient had already been on most migraine medications and was an experienced migraineur.

**Survey Question Three**

The third survey question was intended to concentrate on the topic of whether the HMP provided the migraine patient with the knowledge and skills necessary (Table 13), asking, “Did



the Headache Management Plan provide you (the patient) with the skills and knowledge needed to help better manage migraine headaches at home?”

Table 13

*Knowledge and Skill Provided to Help Manage Migraine at Home*

	Migraine Patients	Neurology Providers
Yes	100% (15)	86% (13)
No	0% (0)	13.33% (2)

All of the migraine patients and 86% of the neurology providers in the survey believed that they had the knowledge and skills to manage migraine at home. Patient explanations included, “I left the clinic understanding everything,” “The plan helped me ask questions,” and “I am more aware of what to watch out for my migraine.” Providers noted overall very positive comments except for one patient who didn’t use the plan as she had forgotten about it. Another provider said that despite having the plan the patient still ended up calling the clinic and went to the emergency room. One provider felt that although the plan was very helpful, it was not the complete package of migraine education but without further recommendations.

**Survey Question Four**

The fourth migraine patient and neurology provider question was related to their overall experience with the HMP (Table 14), requesting input, “How would you rate your overall experience with the Headache Management Plan?”

Table 14

*Overall Experience Rating of the Headache Management Plan*

	Poor	Fair	Good	Very Good	Excellent
Migraine Patients	0% (0)	0% (0)	26.67 (4)	46.67% (7)	26.67% (4)
Neurology Providers	6.67% (1)	13.33 (2)	53.33% (7)	26.67% (4)	0% (0)

In the migraine patient group, the majority at 47% provided the HMP with a rating of very good whereas just over 50% of the neurology providers gave the plan a rating of good. Several providers commented on improved adherence to the migraine treatment.

### **Survey Question Five**

The last survey question was an open-ended question to elicit more depth and richer communication in which respondents could answer in their own words and not a forced yes or no answer. The specific question asked, “Is there anything that you would change on the Headache Management Plan to improve it?” There were 12 responses from of the migraine patient participants and all were positive, noting that they could not think of any changes that needed to be made regarding the HMP. One individual was interested in receiving emails with further information related to migraine. The neurology providers also had 12 responses with most replies surrounding the issue of making the HMP form more user-friendly for the providers. The HMP was completed on paper instead of through the electronic health records (EHR) and the form was cumbersome to fill out, especially for those who had multiple medications and treatments. One provider felt there was redundancy of the form procedure for each appointment as the migraine patient he saw had just been seen four weeks earlier, noting it would be good to have an abbreviated HMP form. Embedding the document into the EHR would solve many of the provider issues. Another provider found the HMP form to be more applicable and useful for patients that had a relatively new diagnosis of migraine and those suffering from episodic versus chronic migraine.

### **Summary of Phase I and II**

The migraine PE survey administered in Phase II was successful in obtaining a robust 80% return rate with neurology providers allowing them to have a loud and clear voice regarding

migraine PE. This robust return spoke to the neurology provider support for migraine PE and their dedication to quality care. However, the migraine patients only had an 18% survey return rate and diverse populations were not represented. Nonetheless, in order to ensure that all populations would be included and that the education is appropriate to all diverse populations, principles of health equity were embedded in all migraine PE methods.

Migraine patients and neurology provider stakeholders found common ground in their preferred method of migraine PE; all individuals compellingly wanted migraine PE to be completed through the neurology provider. Needs assessment perceptions regarding migraine PE differed between groups with the migraine patients feeling that the most important information to know for migraine management was how to prevent migraine by avoiding migraine triggers and the second most important was to have a migraine action plan to manage their migraine at home. Neurology providers on the other hand, overwhelmingly felt that the most important migraine PE content was to understand migraine and related symptoms. The neurology providers' second most important priority was the same as the migraine patients which was to have a migraine action plan to help patients manage their migraine at home.

The results of the Phase II pilot were extremely favorable in both the migraine patient and neurology provider groups, particularly the migraine patients. Although there was little feedback in the explanation sections of each question, it appeared that everyone believed the HMP was easy to understand and effectively provided migraine patients with the knowledge and skills to manage migraine. Some providers felt that more information regarding migraine would be prudent to include, although they didn't offer any specific suggestions. Migraine patients in particular felt more involved in the migraine management patient-centered process. The next chapter provides the summary, discussion, and recommendations of the systems change project.

## Chapter 5

### Discussion, Recommendations, and Conclusion

Migraine is a common condition seen in primary care and neurology clinics which can significantly impact lives. This ailment requires a sizable amount of PE in order for people to take control of migraine and reduce disability. This can be difficult to achieve as clinics are often very busy and lack the time and resources to educate patients. The most common ways of teaching migraine PE skills is by either using verbal exchange at an office visit or by using PE written materials which are not suitable for most people. PE reading materials often have dense and technical language. Fear and embarrassment are likely to hinder many people from asking questions or seeking clarification. Furthermore, cultural and language barriers as well as low literacy levels exacerbate the problem of effective communication. This is of paramount concern because providing good migraine management requires more than just supplying patients with written information to obtain the knowledge and skills needed to independently manage their migraine. It takes an interactive educational process.

Good migraine management starts with a patient and provider collaborative partnership with a thoughtful understanding of the individual's needs, preferences, and values. In addition, it takes open communication that encourages information sharing, choices, and mutual respect which leads to patient empowerment, self-responsibility, and self-management of their chronic disease. This patient-centered approach must to be integrated into an evidence-based system that delivers sound scientific basis for treatment. Combining patient-centered care and evidence-based practice provides the pinnacle of quality and value in health care.

The aim of this quality initiative was to develop a migraine PE program that provided patients with the knowledge and skills necessary to combat migraine headaches by increasing their involvement in decision making and empowering them to be active participants in their own care (Barry & Edgman-Levitan, 2012). The educational process had to be patient-centered to ensure that all diverse populations had equal opportunity to obtain migraine PE; consistent so all migraineurs would have the same educational circumstances; time efficient for neurology providers to use and evidenced-based so that they would have confidence in a new PE process that would provide the best quality and value to the clinic's most important individual—the patient.

This project was completed in two phases. Phase I used survey tools to gain understanding about migraine PE from neurology providers and migraine patients. Phase II of the project created, implemented, and evaluated a PE tool called the HMP.

### **Discussion**

This system change project provided a quality improvement initiative to a Midwestern neurology clinic for adult migraine patients in the area of PE. The HMP is an innovative migraine PE strategy which helps build partnerships between patients and health care providers, bridging the health literacy gap in PE and giving responsibility back to the patient. The process was successful in achieving its objectives which included engaging the stakeholders—migraine patients and providers, reviewing the literature, creating a patient-centered and evidence-based migraine PE program, as well as implementing and evaluating the HMP. It took an orchestration of the systems change process, leadership, and an organizational culture that was open and willing to make the changes needed to succeed. The main discussion points of the systems change project are being presented.

### **Perceptions Regarding Migraine Patient Education**

Phase I of the systems change project provided input from the migraine patients and neurology providers so that all voices could be heard. Having migraine patient and neurology provider stakeholder input was crucial in coming up with the migraine PE program. Needs assessment perceptions regarding migraine PE content differed between groups with the migraine patients feeling that learning how to avoid migraine triggers was the most important PE priority, whereas neurology providers overwhelmingly felt that the most important migraine PE content was to understand migraine and related symptoms. In the Phase II trial, there were also differences in opinions reported between the migraine patient and neurology provider groups with the migraine patients giving the HMP all positive ratings, while the providers scored the HMP lower overall.

The reason for this disparity in perception may be explained by the research observations made by Street and Haidet (2010). Health care providers do not always accurately judge their patients' health perceptions. Although neurology providers are well versed in migraine headaches, it does not necessarily mean that they know what the migraine patient wants or needs. Thus, it is vital to have input from all stakeholders in any quality improvement initiative so that all voices can be heard.

### **Development of a Headache Management Plan**

Understanding educational models and theories to design a program suitable for migraine PE patients was essential. The process began with a thorough review of the literature. Migraine PE research was scant and the vast majority of studies used written materials with minimal or no human contact as well as no mention of cultural diversity of the participants. Although the ICSI headache guidelines and the AAN headache quality measures offered excellent PE content

information, the literature did not supply a blueprint for a migraine PE delivery method. Searching other health care specialty disciplines for PE methods provided great insight into how to educate patients with chronic health conditions. Patient education frameworks using a patient-centered model was intriguing as this mode of PE supplied interactive teaching strategies designed to involve patients in problem solving and addressed cultural, socioeconomic, educational, and psychological needs to promote self-care (Anderson & Funnell, 2005; Philis-Tsimikas et al., 2004; Stone et al., 2005). Using a patient-centered model was critical in tailoring PE to each individual, ensuring that all diverse populations had equal opportunity to obtain migraine PE. This model of patient-centered care delivery was one of the key recommendations provided in the IOM report *Crossing the Quality Chasm* (Richardson et al., 2000).

Foundational theory was a key factor in providing a base to build the PE method. This study relied on Dorothea Orem's nursing theory—the Self-Care Deficit Nursing Theory, principally the basic conditioning that can influence individual values and paths toward self-care which need to be considered when delivering PE to individuals with chronic illness such as migraine (Parker & Smith, 2010). This nursing philosophy is the essence of patient-centered care and was used long before the term patient-centered care was coined.

In addition, Malcolm Knowles' Adult Learning Theory (Holton et al., 2005) supplied insight into what adult learners really need and want to know with regard to PE: patients want to find the solution to their problems and do not want to be inundated with information overload; adults appreciate learning that incorporates the demands of their daily life with active problem-solving; previous life experiences augment the learning process, integrating new ideas and concepts with information that they already know (Holton et al., 2005).

All of the components of the literature review and the stakeholder input came together in the creation of the HMP. The results of the Phase II pilot using the HMP were extremely favorable in both the migraine patient and neurology provider groups, particularly the migraine patients. All of the migraine patients and neurology providers believed the HMP was easy to understand, all of the migraine patients felt more actively involved in their migraine management process, and all of the migraine patients felt that the HMP effectively provided them with the knowledge and skills necessary to manage migraine. Migraine patient participants endorsed the HMP commenting, "I left the clinic understanding everything." Another individual said, "I was able to be a part of the treatment plan." These sentiments are consistent with other patient-centered studies that highlight the importance of patient involvement in decision making and the empowerment for patients that comes from active participation in their own care which will increase self-responsibility (Anderson & Funnell, 2010; Tang et al., 2010). Furthermore, the results of this research project resonate with the work of Epstein et al. (2010) in confirming the attributes of patient-centered care as not only desirable, but crucial to delivering health care that will reduce cost and improve quality and value.

### **Project Limitations**

There were several limitations to this quality improvement project. In the Phase I survey of clinic migraine patients, there was a low response rate of 18%. The Phase I demographic data was also skewed in that all the participants were highly educated and all spoke English. Patients with lower education levels and non-English patients were not represented. In hindsight, the best solution would have been to hand out the surveys after an office visit which could have been completed with the assistance of office staff or an interpreter and then collected by the checkout counter clinic staff. This process would have been much more cumbersome and involved a large



number of staff members but it would have provided a larger response rate as well as inclusion of all race, ethnicity, and educational levels. However, this deficiency was acknowledged and attempts were made to correct it by using a patient-center care model and embedding the principles of health equity in all migraine PE methods to ensure proper education for all diverse populations.

In the Phase II study, there was a small number of patient participants that completed the entire pilot study. In retrospect, it would have been better to have a longer recruitment period to obtain a higher number of study participants and longer follow-up time period to try to reschedule the people who had failed to make it to their follow up appointments. Nonetheless, the migraine patient surveys of those who did participate were almost identical in their exceptionally positive responses to the HMP. Because of the small number of participants, this study cannot be generalized to all populations and more research in this area is needed. Despite the favorable responses in regard to the HMP in both the migraine patient and neurology provider groups, there were few detailed comments elicited from the surveys. With knowledge gained, it would have been better to use more likert scales, pointed questions, or even focus groups to enrich the HMP feedback.

### **Recommendations**

The systems change project has provided the opportunity to learn key concepts and essential components of implementing systems change in a health care setting. Many lessons have been learned along the way. After analysis and synthesis of the study findings, the following migraine PE recommendations can be made.

**Headache Management Plan: The Document**

The HMP was the first attempt towards developing a patient-centered and evidence-based PE tool with stakeholder input. The form had many prerequisites in order to be both migraine patient and neurology provider friendly. Despite the challenges in developing the HMP, the newly created document covered multiple topics of substantial importance in migraine management and was well received by migraine patients and providers.

Although all study participants believed that the HMP was easy to understand, a recommendation for using a two page document allowing for a larger font size of 12 and making some of the words easier to understand would be helpful for patients to read and comprehend. This would also provide less crowding between each HMP section and allow extra room for the section entitled “My Headache Management” which often times can have multiple medications and treatments listed. Using pictures and translating the document into other languages may also be effective to improve comprehension in diverse populations.

The HMP did not supply PE information on understanding migraine, advanced discussions regarding lifestyle changes, or holistic care options. Adjunctive PE materials were suggested by neurology providers in the Phase II surveys and thus, would be appropriate additional migraine PE materials. It was also noted in the Phase I trial that many migraine patients had searched the internet on their own to learn about migraine management. Supplying migraine patients with reputable internet resources would ensure that they are receiving accurate information about migraine.

All of the migraine patients in the Phase II survey believed that they had the knowledge and skills to manage migraine at home. Despite this, there were two individuals who required emergency room care. Thus, even with good migraine PE, it cannot guarantee to take away all

migraine disability. Further studies are needed to evaluate the effectiveness of the HMP tool by measuring PE outcomes with valid and reliable disability measurement tools such as the Headache Impact Test (HIT-6) or the Migraine Disability Assessment (MIDAS). With executive committee support, there may be plans for a second pilot study in the fall of 2014 after the final version of the AAN headache quality measures is published and revision of the HMP is complete. The AAN endorsed disability scales could be used in the next study to track outcome measures.

### **Headache Management Plan: Changing How Providers Practice**

Final survey comments made by the neurology providers focused on how the HMP could be easier to complete. The HMP was completed in paper form which was more work for the providers, as the clinic has had electronic health records (EHR) for over a decade, so this was a step backward with regard to workflow. Embedding the form into the EHR system would be one big leap forward in making the document easier to use. Building structured forms in the EHR could capture data and bring it forward for each patient encounter, eliminating repetition and providing more time at the office visits for the patient. These structured forms will also permit specific outcome data collection into the system.

The patient-centered HMP was a major conceptual change in the way most providers practiced. There is a steep learning curve for some providers who will take time and practice to be efficient at it. Neurology provider focus groups are needed to provide direction in taking the next step of the migraine PE initiative. Receiving input from the pediatric neurologists would be of great value as the HMP could also be transferable to the pediatric migraine population at the neurology clinic. In the future, if this migraine PE program is eventually approved for clinic

wide use, using the Diffusion of Innovation Theory (Stacks & Salwen, 2008) for systems change will be needed to disperse and sustain the initiative throughout the organization.

### **Implications for Nursing Practice**

Patient-centered care and patient education are terms which are unique to nursing and are common concepts taught in nursing schools, entrenched into the education and culture of nursing. The nursing population makes up the vast majority of health care providers and thus, need to lead and educate our colleagues in advancing patient-centered care and PE.

The foundational models of patient-centered care in PE are critical to addressing racial, ethnic, and socioeconomic disparities in health care. Being responsive to individual preferences, needs, and values should guide all clinical decisions. This sentiment was echoed in the American Nurses Association (ANA) Code of Ethics for Nurses which endorses the need for nurses to collaborate in educating all people, regardless of their educational level, culture, values and practices (2001).

The expansion of wisdom and knowledge and ability to be an effective leader to transform nursing practice and patient care will be an important attribute as health care leaders will be faced with new challenges with the changing landscape of health care in the era of the Affordable Care Act. Nurse leaders with a Doctor of Nursing Practice (DNP) degree have the ability to accomplish great things in small as well as larger health care arenas. Advanced practice nurses need to lead in the conversations and partner with other team members to design patient-centered and evidence-based initiatives that commit to solutions that will provide the best quality care delivery.

### **Recommendations for Future Scholarship**

This systems change project began as a quality improvement proposal within a social justice framework to improve migraine PE in all populations. Although the project was geared toward marginalized groups, they were not represented in Phase I of the study and minimally in Phase II. Health disparities do exist in Minnesota and around the US. A recent legislative special report from the Minnesota Department of Health, *Advancing Health Equity in Minnesota* (2014) revealed the alarming reality that Minnesota has substantial health disparities “because the opportunity to be healthy is not equally available everywhere or for everyone in the state” (p.5). Furthermore, review of the literature uncovered the shocking statistics that only 12 percent of adults have proficient health literacy and nearly nine out of ten adults in America lack the skills needed to manage their health (US Department of Health and Human Services (HHS), Office of Disease Prevention and Health Promotion, n.d.).

These obvious health iniquities will lead to insufficient migraine PE for most populations, particularly marginalized groups, thereby producing negative health outcomes. These health disparities need to be addressed by all health care providers in small and large health care systems. More research is needed to better understand the health perceptions of diverse populations regarding migraine and PE. Nurse leaders offering focus groups in urban clinics could be one way of gaining better insight into these health concerns.

This systems change project innovation could be used as a template for other PE quality improvement studies in the Midwestern neurology clinic. The project has the potential for transferability to primary care clinics with large volumes of migraine patients in need of PE.

### **Conclusion**

This systems change project provided a patient-centered and evidence-based educational plan for migraine patients in a Midwestern neurology clinic. This initiative was not intended to be a migraine patient education panacea. Based on the findings and the knowledge gained from the innovation, improving migraine care is a journey. The end of this systems change project is just the beginning of the quality improvement quest. At the helm of every quality improvement venture there has to be a social justice lens that frames and guides the initiative to help champion the needs of all populations resulting in improvements that endure and pervade the entire organization. This research contribution is the first step of the migraine management journey.

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Appendix A—Table of Characteristics—Quantitative

<b>Study (Author, Year)</b>	<b>Purpose</b>	<b>Population/ Sample</b>	<b>Research Design</b>	<b>Intervention</b>	<b>Comparison</b>	<b>Outcome Measures/Scale s</b>	<b>Results</b>
Hu et al. (2004)	Evaluate effectiveness of a managed care migraine education program	Managed Care Migraineurs N= 2232 Intervention group=1373 Controls= 859	Quasi-Experimental	Written migraine educational brochures mailed monthly for 6 months	Intervention group and the control group (usual care)	MTAQ Total MIDAS Health Survey SF-12	P<0.05 P<0.001 NS
Nicholson et al. (2005)	Evaluate effectiveness of a self-administered migraine intervention	Migraineurs Age 18-65 N=21 95% Female 90%Caucasian 100% High school diploma	Quasi-Experimental	Self-administered written migraine educational materials and stress management audiotapes with tailored messaging	Pre and post intervention at 15 weeks	Headache related outcomes (frequency, treatment response, and disability) MIDAS	P<.001 P<.05
Campinha-Bacote et al. (2005)	Evaluate effectiveness of a managed care migraine education program	Managed Care Migraineurs N=789	Quasi-Experimental	Written migraine educational materials mailed monthly for 6 months	Pre and post intervention	MTAQ divided: 1-Symptoms 2-Symptoms 3-Frequency 4-Frequency 5-Knowledge 6-Knowledge 7-Economics 8-Economics 9-Satisfaction	Divided result P= 0.0218 P= 0.0010 P= 0.0270 NS P<0.0001 NS P<0.0001 P<0.0018 P<0.0001

Study (Author, Year)	Purpose	Population/ Sample	Research Design	Intervention	Comparison	Outcome Measures/Scales	Results
Rothrock et al. (2006)	Evaluate effectiveness of patient education to migraine burden	Migraineurs Age 17-62 N=100 Convenience sample at Headache clinic Intervention group=50 Control=50	RCT	3 migraine educational classes, 30-45 min. each by lay migraineurs	Intervention group and the control group At baseline, 1, 3, and 6 months	MIDAS  Headache days per month	P<.05  Intervention group: From 14 to 8 Control group: No change
Cady et al. (2007)	Evaluate effectiveness of migraine educational program	Migraineurs N=180 Randomly divided into 4 groups	RCT	12 minute educational migraine CD with nurse attending at varying intensities	A) DVD + Nurse intro. B) DVD + Nurse help C) DVD + No nurse D) No DVD	Migraine Questionnaire  No noted reliability validity	Comparisons: Group A to D: P<.001 Group B to D: P<.001 Group C to D: P<.01
Matchar et al. (2008)	Evaluate effectiveness of migraine management program	Migraineurs N=576 Intervention group=305 Control group=309	RCT	Educational program with a mid-level provider, group or individual	Intervention group and the control group at baseline, 6, and 12 months	MIDAS  General Health and Quality of Life SF-36	P=.008  P<.05



<b>Study (Author, Year)</b>	<b>Purpose</b>	<b>Population/ Sample</b>	<b>Research Design</b>	<b>Intervention</b>	<b>Comparison</b>	<b>Outcome Measures/Scale</b>	<b>Results</b>
Smith et al. (2010)	Effect of education on frequency of migraine	Migraineurs N=228 92% Females	Quasi-Experimental	Written migraine materials given at an office visit	Pre and post at baseline, 3, 6, and 12 months	Headache days HIT-6 Migraine MSQ Emotional-Restrictive-Preventative-	P<.001 P<.01 P<.001 P<.01 P<.01 P<.05
Bromberg et al. (2012)	Effect of a web-based education program on migraine burden	Migraineurs N=213 Intervention group= 95 Control group= 94 Age 18-65 Power analysis	RCT	Web-based education intervention: 1 <sup>st</sup> month: 8, 20 min. sessions, then 5, 20 minute sessions	Intervention group and control group at baseline, 1, 3, and 6 months	Headache record MIDAS DASS: Depression Anxiety Stress Self-efficacy Locus of control	No data No data  P=.0028 NS P=.0079 P=.0018 P=.0018
Dindo et al. (2012)	Effect of an intense 5 hour educational program on migraine and depression	Comorbid migraine and depression N= 45 Intervention group =31 Control group= 14 Age 18-70	RCT	Five hour workshop: 1 hour migraine education and 4 hour acceptance and commitment training (ACT)	Intervention group and control group (usual care)  Over 12 weeks	HDI  Inventory of depression and Anxiety Symptoms (IDAS)	P=.006  P=.009

Appendix B

Oxford Centre for Evidence-Based Medicine 2011 Levels of Evidence (OCEBM)

Question	Step 1 (Level 1)	Step 2 (Level 2*)	Step 3 (Level 3)	Step 4 (Level 4*)	Step 5 (Level 5)
<b>How common is the problem?</b>	Local and current random sample surveys (or censuses)	Systematic review of surveys that allow matching to local circumstances**	Local non-random sample**	Case-series**	n/a
<b>Is this diagnostic or monitoring test accurate?</b> (Diagnosis)	Systematic review of cross sectional studies with consistently applied reference standard and blinding	Individual cross sectional studies with consistently applied reference standard and blinding	Non-consecutive studies, or studies without consistently applied reference standards**	Case-control studies, or poor or non-independent reference standard**	Mechanism-based reasoning
<b>What will happen if we do not add a therapy?</b> (Prognosis)	Systematic review of inception cohort studies	Inception cohort studies	Cohort study or control arm of randomized trial*	Case-series or case-control studies, or poor quality prognostic cohort study**	n/a
<b>Does this intervention help?</b> (Treatment Benefits)	Systematic review of randomized trials or <i>n</i> -of-1 trials	Randomized trial or observational study with dramatic effect	Non-randomized controlled cohort/follow-up study**	Case-series, case-control studies, or historically controlled studies**	Mechanism-based reasoning
<b>What are the COMMON harms?</b> (Treatment Harms)	Systematic review of randomized trials, systematic review of nested case-control studies, <i>n</i> -of-1 trial with the patient you are raising the question about, or observational study with dramatic effect	Individual randomized trial or (exceptionally) observational study with dramatic effect	Non-randomized controlled cohort/follow-up study (post-marketing surveillance) provided there are sufficient numbers to rule out a common harm. (For long-term harms the duration of follow-up must be sufficient.)**	Case-series, case-control, or historically controlled studies**	Mechanism-based reasoning
<b>What are the RARE harms?</b> (Treatment Harms)	Systematic review of randomized trials or <i>n</i> -of-1 trial	Randomized trial or (exceptionally) observational study with dramatic effect			
<b>Is this (early detection) test worthwhile?</b> (Screening)	Systematic review of randomized trials	Randomized trial	Non-randomized controlled cohort/follow-up study**	Case-series, case-control, or historically controlled studies**	Mechanism-based reasoning

OCEBM Levels of Evidence Working Group\*. "The Oxford 2011 Levels of Evidence". Oxford Centre for Evidence-Based Medicine. <http://www.cebm.net/index.aspx?o=5653>

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## Appendix C

## Summary of Articles included in the Integrative Review

Author /Year	Sample	LOE	Conclusion
Summary of Migraine Patient Education Studies			
Hu et al. (2004)	N=2232	III	Mailed written PE materials reduce migraine disability
Nicholson et al. (2005)	N=21	IV	Self-administered written PE with stress management audiotapes reduce migraine disability
Campinha-Bacote et al. (2005)	N=789	III	Mailed written PE materials reduce migraine disability
Rothrock et al. (2006)	N=100	II	Lay migraineurs classes reduce migraine disability
Cady et al. (2007)	N=180	II	Migraine PE DVD with nurse improves understanding of migraine
Matchar et al. (2008)	N=576	II	PE program with mid-level providers, 1:1 or group reduces migraine disability
Smith et al. (2010)	N=228	III	Written PE materials at office visit improves migraine disability
Bromberg et al. (2012)	N=213	III	Web-based PE program lost data on migraine disability. Improved depression.
Dindo et al. (2012)	N=45	III	Five hour workshop for comorbid migraine & depression reduced migraine disability & improved depression
Craddock & Ray (2012)		IV	Summary of current evidence on migraine PE and providing a foundation for family teaching

## Appendix D

### Phase I Neurology Provider Informed Consent

**Introduction:**

You are invited to participate in a research study investigating patient education for adult migraine headache patients. This study is being conducted by Ann Rehtzigel, a Doctor of Nursing student at St. Catherine University under the supervision of Dr. Kathleen Smith, a faculty member in the Department of Nursing. You were selected as a possible participant in this research because you are a provider at the Noran Neurological Clinic who cares for adult patients with migraine. Please read this form and ask questions if needed before you agree to be in the study.

**Background Information:**

This survey is a part of a systems change project with the purpose of improving quality of care and reducing health disparities for patients at Noran Neurological Clinic in the area of adult migraine patient education. This process begins by getting input from the stakeholders involved, including neurology providers and migraine patients of diverse cultural, educational, and socioeconomic backgrounds to better understand current migraine patient education practices and opinions regarding migraine education. The information you provide is confidential and will be published only in statistical summary form. You will not be identified in any way. The information will be analyzed and presented to the Noran Neurological Clinic Board for discussion and recommendations regarding ways to improve current methods of adult migraine patient education. Approximately 40 providers and 200 migraine patients are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to answer questions on a survey regarding migraine patient education. This study will take approximately 10 minutes over one session.

**Risks and Benefits of being in the study:**

The study has the minimal risk of inconvenience. There are no direct benefits to you for participating.

**Confidentiality:**

All of the information you provide is confidential and will be published only in group statistical summary form. You will not be identified. I will keep the research results in a locked file cabinet in my home and only Ann Rehtzigel and my advisor will have access to the records while I work on this project. I will finish analyzing the data by June 30, 2013. I will then destroy all original reports and identifying information that can be linked back to you.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with Noran Neurological Clinic or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

**Contacts and questions:**

If you have any questions, please contact me, Ann Rehtzigel at (507) 298-0550. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Kathleen Smith at (651) 690-6580, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board at (651) 690-7739.

**Statement of Consent:**

You are making a decision whether or not to participate. Your electronic signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time. You may keep a copy of this form for your records.

I consent to participate in the study.

Electronic Signature of Participant with Stamped Date

## Appendix E

## Phase I Migraine Patients Informed Consent

**Introduction:**

You are invited to participate in a research study investigating adult patient education for migraine headaches. This study is being conducted by Ann Rehtzigel, a Doctor of Nursing student at St. Catherine University under the supervision of Dr. Kathleen Smith, a faculty member in the Department of Nursing. You were selected as a possible participant in this research because you have been a Noran Clinic patient for approximately six months to one year, and you are age 18 and above with a diagnosis of migraine headache. Please read this form and ask questions if needed before you agree to be in the study.

**Background Information:**

The purpose of this study is to understand the views of both adult migraine patients and neurology providers regarding adult migraine patient education. Approximately 200 patients and 40 providers are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to answer questions on a survey regarding migraine patient education. This study will take approximately 15 minutes over one session.

**Risks and Benefits of being in the study:**

The study has the minimal risk of inconvenience.

There are no direct benefits to you for participating in this research.

**Confidentiality:**

All of the information you provide is confidential and will be published only in group statistical summary form. You will not be identified. I will keep the research results in a locked file cabinet in my home and only Ann Rehtzigel and my advisor will have access to the records while I work on this project. I will finish analyzing the data by June 30, 2013. I will then destroy all original reports and identifying information that can be linked back to you.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with Noran Neurological Clinic or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

**Contacts and questions:**

If you have any questions, please feel free to contact me, Ann Rehtzigel at (612) 879-1000. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Kathleen Smith at (651) 690-6580, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

You may keep a copy of this form for your records.

**Statement of consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time.

I consent to participate in the study.

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Signature of Participant and Date

## Appendix F

## Phase II Neurology Providers Informed Consent

**Introduction:**

You are invited to participate in a research study evaluating an evidence-based and patient-centered headache management plan for adult migraine headache patients. This study is being conducted by Ann Rehtzigel, a Doctor of Nursing Practice student at St. Catherine University under the supervision of Dr. Kathleen Smith, a faculty member in the Department of Nursing. You were selected as a possible participant in this research because you are a Noran Clinic provider. Please read this form and ask questions before you agree to be in the study.

**Background Information:**

The purpose of this study is to evaluate an evidence-based and patient-centered headache management plan in a neurology clinic. Approximately 5 providers and 25 patients are expected to participate.

**Procedures:**

If you decide to participate, you will be involved in a pilot study using the headache management plan. This form will be completed in collaboration with 5 of your migraine patients at their routine office visits, if they chose to participate. If they choose not to participate, you will then provide usual headache care without the headache management plan.

The headache management plan is a form that you will fill out with each migraine study patient who participates at their routine appointment. You will be writing down specific information discussed at the office visit, including the sections on patient's headache diagnosis, how their headaches are doing, the headache management plan, and patient education for the patient participant to take home as their own individualize migraine headache plan of care.

A scheduled follow up appointment will be made approximately 4-6 weeks afterward with each patient participant for routine evaluation of migraine headache status. You will complete a new headache management plan with the study patient at that time.

Immediately following the second appointment, you will be asked to fill out a survey regarding the headache management plan as it relates to that particular patient. You will also ask the patient participant to fill out a similar survey regarding the headache management plan. This study will take approximately 70 minutes with a total of 2 sessions per patient.

**Risks and Benefits of being in the study:**

There is minimal risk of inconvenience.

There is no direct benefit to you for participating in this research.

**Confidentiality:**

All of the information you provide is confidential and will be published only in group summary form. You will not be identified. The research results will be locked in a cabinet at the home of Ann Rechtzigel and only she and her advisor will have access to the records while working on the project. Analysis of the data will be finished by May 31, 2014. All original reports and identifying information that can be linked to you will be destroyed, except for the Noran Clinic headache management plan form which will be a part of the medical records.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the Noran Neurological Clinic or St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

**Contacts and questions:**

If you have any questions, please feel free to contact Ann Rechtzigel at (612) 879-1000. You may ask questions now, or if you have any additional questions later, the faculty advisor, Kathleen Smith at (651) 690-6507 will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time. You may keep a copy of this form for your records.

I consent to participate in the study.

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Signature of Participant

Date

## Appendix G

### Phase II Migraine Patients Informed Consent

**Introduction:**

You are invited to participate in a research study evaluating a patient-centered headache management plan for adult migraine headache patients. It is an individualized written plan of care that is made together today for you to follow after your appointment, to help you manage your migraine at home. This study is being conducted by Ann Rechtzigel, a Doctor of Nursing Practice student at St. Catherine University under the supervision of Dr. Kathleen Smith, a faculty member in the Department of Nursing. You were selected as a possible participant in this research because you are a Noran Clinic patient who is age 18 and above with a diagnosis of migraine headache. Please read this form and ask questions before you agree to be in the study.

**Background Information:**

The purpose of this study is to evaluate a patient-centered headache management plan in a neurology clinic. Five providers and 25 patients are expected to participate. The two migraine study office visits will be in place of your usual office visits, so there are no differences regarding insurance or charges for the office visits.

**Procedures:**

If you decide to participate, you will be involved in a pilot study using a new form called the headache management plan which we will complete together today. This will add 5-10 minutes onto your appointment. A scheduled follow up appointment will be made in 4-6 weeks with me for another routine evaluation of your migraine headache status. We will complete a new headache management plan at that time. Right after the second appointment, I will ask you to fill out a short survey regarding the headache management plan which will take 10 minutes. This study will take approximately 70 minutes with a total of 2 sessions.

**Risks and Benefits of being in the study:**

There is minimal risk of inconvenience. There is possible benefit of improving headache management.

**Confidentiality:**

All of the information you provide is confidential and will be published only in group summary form. You will not be identified. The research results will be in a locked cabinet at the home of Ann Rechtzigel and only she and her advisor will have access to the records while working on the project. Analysis of the data will be finished by May 31, 2014. All original reports and identifying information that can be linked to you will be destroyed, except for the headache management plan form, which will be a part of your medical records.



**Voluntary nature of the study:**

Participation in this research study is voluntary. If you decide not to participate, it is okay. We will continue with a regular office visit to discuss your migraine headaches. Your decision whether or not to participate will not affect your relationship with the Noran Neurological Clinic, St. Catherine University, or Ann Rechtzigel as a researcher or neurology provider in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

**Contacts and questions:**

If you have any questions, please feel free to contact your neurology provider or Ann Rechtzigel at (612) 879-1000. You may ask questions now, or if you have any additional questions later, the faculty advisor, Kathleen Smith at (651) 690-6507 will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time. You may keep a copy of this form for your records.

I consent to participate in the study.

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Signature of Participant

Date

Appendix H

Phase I Adult Migraine Patient Education Survey: For Neurology Providers

Directions: Please check, number, or fill in your responses to the questions below. You may skip questions that you do not wish to answer. After you are finished answering the questions, please send back the survey as instructed. \*\* Please respond within two weeks.

**1) How do currently provide patient education for your adult migraine headache patients? Check all that apply.**

- Verbal migraine information given at an office visit
- Written information about migraine from a website
- The Minnesota Headache Center folder
- Other \_\_\_\_\_

**2) Do you use the same patient education information for all adult migraine headache patients, including populations of cultural, educational, and socioeconomic diversity?**

- Yes
- No

**3) If you do not use the same patient education information for all adult migraine headache patients, how do you educate these diverse populations?**

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**4) Do you feel that your adult migraine patients are getting the education and skills necessary to manage their migraine headaches?**

Never                      Rarely                      Sometimes                      Often                      Always

**5) What do you think is important for adult migraine patients to know in order to manage migraine headaches? Please number in the order of importance to you, starting with number 1 as most important and number 6 as least important.**

- Understanding migraine and the related symptoms
- Understanding migraine medication effects and side effects
- Learning how to make an action plan and be prepared to get rid of migraine headaches
- Understanding how to prevent migraine headaches by avoiding migraine triggers
- Understanding about diet and lifestyle changes to help live better with migraine
- Learning about non-medication treatments such as physical therapy, biofeedback, and others to help prevent migraine

**6) What ways would your adult migraine patients learn best to manage their migraine? Please number in order, starting with number 1 as the best.**

- Reading migraine information on your own from the clinic
- Reading migraine information on your own from websites recommended by the clinic
- Talking to my provider (doctor, nurse practitioner, or physician assistant) at an office visit
- Individualized migraine education session, separate from your office visit
- A clinic web-based video or PowerPoint presentation
- Group education session with other migraine patients

**7) In your opinion, what would be the average amount of time needed to provide adult patients with the knowledge and skill necessary to manage migraine headaches?**

- 5-10 minutes
- 11-15 minutes
- 16-30 minutes
- 31-45 minutes
- 46-60 minutes

Other: \_\_\_\_\_

**8) Do you feel that you have enough time in your schedule to adequately educate your adult migraine patients?**

Never                      Rarely                      Sometimes                      Often                      Always

**9) Would you be supportive of changes in adult migraine patient education at the neurology clinic to promote self-management in all migraine populations?**

Strongly                      Somewhat                      Neutral                      Somewhat favor                      Strongly favor  
opposed                      opposed

**10) Please add any additional comments you have regarding adult migraine patient education at the neurology clinic below:**

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**Thank you for participating in this survey. Input from neurology providers is important to improve patient care.**

Appendix I

Phase I Adult Migraine Patient Education Survey: For Migraine Patients

Below is a survey related to your neurology clinic migraine education experience and opinion regarding migraine patient education. After you have finished answering the questions, please place the survey and consent form in the self-addressed stamped envelope provided, and mail it back to the clinic within two weeks.

Directions: Please check, number, or circle your response to the questions below.

**1) What type of education did you receive for your migraine headaches?  
Please check all that apply.**

- My provider (doctor, nurse practitioner, or physician assistant) talked to me about how to manage my migraine headaches
- I was given written migraine headache information from a website
- I was given the Minnesota Headache Center Folder that has migraine headache information in it
- Other \_\_\_\_\_
- Prefer not to respond

**2) How would you rate your overall migraine patient education experience at the clinic?**

**Poor                      Fair                      Good                      Very Good                      Excellent**

\_\_\_ Prefer not to respond

**3) How confident are you in managing your migraine headaches at home?**

Not at all                      Slightly                      Somewhat                      Very confident                      Extremely  
confident                      confident                      confident                      confident                      confident

\_\_\_ Prefer not to respond

**4) What are the important things to know in order for you to manage your migraine headaches? Please number in the order of importance to you, starting with 1 as most important and 6 as least important.**

- Understanding migraine and the related symptoms
- Understanding migraine medication effects and side effects
- Learning how to make an action plan and be prepared to get rid of migraine headaches
- Understanding how to prevent migraine headaches by avoiding migraine triggers
- Understanding about diet and lifestyle changes to help live better with migraine
- Learning about non-medication treatments such as physical therapy, biofeedback, and others to help prevent migraine
- Prefer not to respond

**5) What would be the best way for you to learn the information needed to manage your migraine? Please number in order, starting with number 1 as the best.**

- Reading migraine information on your own from the clinic
- Reading migraine information on your own from websites recommended by the clinic
- Talking to my provider (doctor, nurse practitioner, or physician assistant) at an office visit
- Individualized migraine education session, separate from your office visit
- A clinic web-based video or PowerPoint presentation
- Group education session with other migraine patients
- Prefer not to respond

**6) What could we do at the neurology clinic to make your migraine education experience better?**

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**7) This section of the survey asks about demographic information about you to help understand the diversity of the neurology clinic patient population.**

**Age:** \_\_\_\_\_

**Gender:** \_\_\_\_\_

**Language you speak at home:** \_\_\_\_\_

**Number of years of schooling:** \_\_\_\_\_

**Prefer not to respond:** \_\_\_\_\_

**Thank you for taking this survey! Your opinion is important. Please place the survey and consent form in the self-addressed stamped envelope provided, and mail it back to the neurology clinic within two weeks.**

**Appendix J  
HEADACHE MANAGEMENT PLAN**

Name: \_\_\_\_\_ Account Number: \_\_\_\_\_ Date: \_\_\_\_\_ Provider: \_\_\_\_\_

**MY DIAGNOSIS:** \_\_\_\_\_

**HOW AM I DOING?**

Number of headache days per month: \_\_\_\_\_ ER/Urgent care visits this year \_\_\_\_\_

HIT-6 Score: \_\_\_\_\_ WHAT DOES IT MEAN? My headaches impact my life:  little  some  substantially  very severely

Number of days per month using prescribed and/or over the counter abortive medication (to relieve headache): \_\_\_\_\_

Good Headache Control  Fair Headache Control  Poor Headache Control

**MY HEADACHE MANAGEMENT:**

Abortive Medication (to relieve headache): \_\_\_\_\_

Abortive Medication Reduction Plan (if needed): \_\_\_\_\_

Preventative Medication (to prevent headaches from coming): \_\_\_\_\_

Rescue Plan (medication plan if abortive medication is not enough): \_\_\_\_\_

Non-drug Treatments: \_\_\_\_\_

**PATIENT EDUCATION:**

Signs that I have a headache coming on:

Vision changes  Weakness  Tired  Sick to stomach  Increased energy  Trouble walking  Numbness & tingling  Mood changes  Food Cravings  Other \_\_\_\_\_

Things that trigger my migraine headaches:

FOOD or DRINK:  Chocolate  Artificial sweeteners  Nitrates  MSG (monosodium glutamate) & other spices/seasonings  Caffeine  Alcohol  Other \_\_\_\_\_

EXPOSURE TO:  Weather changes  Strong smells  Bright lights  Loud noises

EMOTIONAL FACTORS:  Stress  Anger  Excitement  Sadness

PHYSICAL FACTORS:  Hormone changes (including menstrual cycle, estrogen & birth control medication)  Sleep (too little or too much)  Skipping meals  Smoking  Muscle tightening in neck or jaw  Workplace Ergonomics

What I can do if I have a migraine:

- \*Take my abortive (relief) medication at the first sign of pain      \* Apply a cold pack to the area of head pain
- \* Lie down in a dark room      \*Use relaxation skills such as deep breathing or meditation
- \*Do not routinely take headache abortive (relief) medication more than twice a week to prevent rebound headaches

Things I can do to manage my headaches:

- \*Stay away from my triggers      \*Reduce stress      \*Keep routine sleep patterns      \*Exercise regularly      \*Avoid caffeine, alcohol, & smoking
- \* Keep healthy eating patterns      \*Keep medication on hand and take as prescribed to avoid an emergency room visit
- \*Use a headache diary to track my headaches and triggers

Call my provider when:

- I have a headache that significantly affects my daily activities and lasts over 72 hours despite using my medications
- I have side effects from my medications that won't go away

**\*Noran Clinic Phone Number: (612) 879-1000**

**\*Please bring your headache diary to every appointment\***



Appendix K

Headache Management Program Costs

<b>Activity</b>	<b>Time</b>	<b>People Involved</b>	<b>Hourly Rate</b>	<b>Cost</b>
Phase I survey preparation	25 hours	Researcher	NA	In-kind donation
Phase I survey analysis	20 hours	Researcher	NA	In-kind donation
Development of the Headache Management Plan	30 hours	Researcher	NA	In-kind donation
Phase II study and survey preparation	45 hours	Researcher	NA	In-kind donation
Phase II study staff training	2.5 hours	Researcher	NA	In-kind donation
	30 minutes each = 1.5 hours	3 Neurologists	\$110	\$165
	30 minutes each = 1 hour	2 Physician Assistants	\$54	\$54
Phase II study additional patient office visit time	1 hour in total	3 Neurologists	\$110	\$110
	40 minutes in total	2 Physician Assistants	\$54	\$36
Phase II study analysis	20 hours	Researcher	NA	In-kind donation

Total: \$365
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Appendix L

Phase II Headache Management Plan Survey for Providers

Below is a survey related to your headache management plan experience and opinions regarding this new way of caring for migraine headache patients. Please fill out this survey on each of your five migraine patient participants. You are not obligated to complete the survey; however, we encourage you to do so. Once you have finished answering the questions on both sides of this page, please give the survey to your secretary.

**Patient Demographics:**

Patient account number: \_\_\_\_\_

Age: \_\_\_\_\_

Gender: \_\_\_\_\_

Language spoken: \_\_\_\_\_

Number of years of schooling: \_\_\_\_\_

Was the headache management plan easy for the patient to understand?    Yes    No

Explain:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Do you feel that the headache management plan increased patient involvement in the headache management process?

Yes    No

Explain:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Did the headache management plan provide the knowledge and skills needed for the patient to self-manage their migraine?

- Yes
- No

Explain:

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How would you rate your overall experience with the headache management plan as it relates to this patient?

- Poor
- Fair
- Good
- Very Good
- Excellent

Explain:

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Is there anything that you would change on the headache management plan form to improve it based on this patient?

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**Thank you for taking this survey. Please hand in the survey to your secretary.**

Appendix M

Phase II Headache Management Plan Survey for Patients

Account# \_\_\_\_\_

Below is a survey related to your headache management plan experience and opinions regarding this new way of caring for migraine headache patients. Please answer the questions below as your input is important to us. You are not obligated to complete the survey; however, we encourage you to do so. After you have finished answering the questions, please give the survey to the person at the checkout counter.

Was the headache management plan easy to understand?

- Yes     No

Explain:

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Did the headache management plan allow you to be more actively involved in the planning of your migraine treatment?

- Yes     No

Explain:

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**Please turn the page to finish the survey**

Did the headache management plan provide you with the knowledge and skills needed to help you to better manage your migraine headaches at home?

- Yes
- No

Explain:

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How would you rate your overall experience with the headache management plan?

- Poor
- Fair
- Good
- Very Good
- Excellent

Explain:

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Is there anything that you would change on the headache management plan form to improve it?

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**Thank you for taking this survey. Please hand in the survey at the checkout counter.**