

Epilepsy Knowledge Profile and Epilepsy Self-Management; A Quality Improvement Study

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Author's note

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Abstract

Background and Purpose: Epilepsy is a chronic neurological disorder marked by recurrent seizures. It affects approximately 60 million people worldwide and is the most prevalent chronic neurological condition globally. This quality improvement study was conducted to evaluate whether there was a correlation between general epilepsy knowledge and epilepsy self-management practices in adult patients with epilepsy.

Method: A descriptive cross-sectional survey was conducted between January 2019 to February 2019 in a metropolitan adult neurology clinic. Two standardized questionnaires, the Epilepsy Knowledge Profile- general (EKP-Q) and the Adult Epilepsy Self-Management Measurement Instrument (AESSMI), were emailed using a PsychData link to patients diagnosed with epilepsy.

Results: A total of 39 participants responded to the survey. Four only filled out the demographics part and did not complete the questionnaires. Thirty-five completed both questionnaires but only 29 had valid data on the AESSMI part of the questionnaires. A simple bivariate analysis was completed using the variable EKP-Q and AESSMI. A weak positive correlation between epilepsy knowledge and epilepsy self-management was found with a Pearson correlation coefficient ($r=0.378$). The level of correlation significance was established at a p -value of 0.05.

Discussion: The hypothesis for this study expected a strong positive correlation between epilepsy knowledge and epilepsy self-management. The results found a weak positive correlation due to limitations of time and missing data. Recommendations for future studies is for data to be collected over more extended periods with incentives given to participants for completing the surveys. It is also recommended that future patient education programs focus on both aspects of knowledge and self-management for improved patient outcomes in epilepsy.

Epilepsy Knowledge Profile and Epilepsy Self-Management; A Quality Improvement Study

Chapter 1: Problem

Epilepsy is a chronic neurological disorder marked by recurrent seizures. The International League Against Epilepsy (ILAE), defines a seizure as the transient occurrence of symptoms caused by excessive abnormal electrical discharge in the brain (International League Against Epilepsy, 2018). It affects approximately 60 million people worldwide and is the most prevalent chronic neurological condition globally. An estimated 2.4 million people are diagnosed with epilepsy each year with the incidence being higher in low and middle-income countries compared to the high-income countries such as the United States (World Health Organization, 2017). Epilepsy incidence in the United States is currently at 48 per 100,000 people in the general population. Its prevalence is on the rise with the number of adults living with active epilepsy rising from 2.3 million in 2010 to 3 million in 2015. The number of children with the condition increased from 450,000 in 2007 to 470,000 in 2015 (Centers for Disease Control and Prevention, 2018). Epilepsy is now the 4th most common neurological condition after Migraines, Strokes and Alzheimer's disease respectively (Epilepsy Foundation, 2018).

The diagnosis of epilepsy is usually made after an occurrence of two or more unprovoked seizures at least 24 hours apart. One unprovoked seizure with at least 60% risk of recurrence as determined by medical evaluation also confers the diagnosis of epilepsy (ILAE, 2018). In clinical practice, epilepsy is explained as having recurrent seizures that are not caused by a known and reversible medical condition such as alcohol withdrawal or very low blood sugar (Epilepsy Foundation, 2018). Approximately 50% of patients with epilepsy become seizure-free on their first anti-seizure medication (Kwan & Brodie, 2001). The other 50% of patients that fail to become controlled require two or more antiseizure medications long term. The likelihood of

sustained seizure freedom does not improve much after the third medication is added and the chance of true seizure freedom was shown to drop to less than 10% after the third drug was tried and failed (Brodie, 2010). The standardized mortality ratio for patients with recurrent seizures is 4.69 (Sirven, Garcia, & Eichler, 2017). This means that the likelihood of death in a person with uncontrolled epilepsy is more than four times higher than that of the general population (Sirven et al., 2017).

Epilepsy carries significant financial and social costs. The total direct cost of epilepsy in the United States is estimated at 15.5 billion dollars yearly (CDC, 2018), with emergency services and hospital admissions taking up most of that cost. Other direct costs include medications, diagnostics, rehabilitation, and special equipment (Begley & Durgin, 2015). The indirect social costs of epilepsy are also significant. The most prevalent indirect costs associated with this condition are, (a) lost productivity due to lost working days, (b) reduced quality of life due to driving limitations, (c) diminished psychological wellbeing, and (d) detrimental effects on education in children (Smith, McKinlay, Wojewodka, & Ridsdale, 2017). Because epilepsy is among the top 10 most expensive chronic conditions in the United States, reducing unnecessary hospital admissions by promoting patient self-management is an essential factor in helping relieve the financial burden on healthcare systems

Clinical Needs Assessment and Specific Aim

Epilepsy is a chronic condition, and therefore, self-management is an important aspect of managing epilepsy. Educating patients and their caregivers about the treatments and risks associated with poor adherence is commonly practiced by clinicians during patient encounters (Doughty, Baker, Jacoby, & Lavaud, 2003). Certain behavioral interventions such as sleep hygiene and alcohol avoidance are part of that informal education given to patients with epilepsy

(Malek, Heath, & Greene, 2017). Self-management education is also part of the routine education given by clinicians while evaluating patient concerns and answering questions related to epilepsy. However, patients have routinely reported dissatisfaction with the amount of contact time they got with providers and that the information received was insufficient to address the many issues they faced living with epilepsy (Doughty et al., 2003). Formal outpatient educational programs for patients with epilepsy are few, and the evidence for developing such programs as standard outpatient care is still small compared to other chronic diseases such as diabetes (Smith et al., 2017).

Numerous research results have shown a high correlation between patient empowerment and medication adherence as part of clinical outcomes evaluation. In a review of the association between patient empowerment and adherence, Náfrádi, Nakamoto, & Schulz (2017) posited that the highly empowered patients can be assumed to be adherent, but that it was important to make a distinction between highly empowered and highly literate. Highly empowered patients may believe that they can make treatment decisions by themselves overruling the provider's prescription while patients with high levels of health literacy, without corresponding high levels of patient empowerment, were shown to have unnecessary dependence on healthcare providers (Náfrádi, Galimberti, Nakamoto, & Schulz, 2016).

In other parts of the world, a basic lack of medical knowledge along with poor literacy was shown to directly contribute to poor treatment adherence and lower quality of life (Magill et al., 2015). Social beliefs about epilepsy also contribute highly to poor outcomes related to medication non-adherence and poor health-seeking behaviors (Dua, De Boer, Prilipko, & Saxena, 2006). A systematic review of epilepsy treatment in developing countries identified a

treatment gap in epilepsy influenced by limited knowledge, poverty, cultural beliefs, and stigma associated with epilepsy (Mbuba, Ngugi, Newton, & Carter, 2008)

The specific aim of this study was to evaluate what patients with epilepsy know about the condition and how that knowledge correlates with their self-management practices. The overall significance of the project contributed to the body of evidence supporting epilepsy literacy and self-management programs. The study will also serve as a basis for more research into what educational modalities are needed to improve patients with epilepsy outcomes.

The PICO Question

The Population, Intervention, Comparison, Outcome (PICO) question for this project was as follows; In adult patients with epilepsy, does the level of epilepsy knowledge correlate with their self-management practices? The population of interest was adult patients age 18 and older with a diagnosis of epilepsy. The intervention was an assessment of their epilepsy knowledge using an epilepsy knowledge profile tool while the comparison was their score on the epilepsy self-management tool. Whether there was a correlation between the two scores was the assessed outcome of the project.

Population. The population involved in this study was adult patients routinely seen for epilepsy care at an outpatient neurology clinic in Dallas. The age of the study participants ranged from 18 to 80, and they were required to be able to read and understand English.

Issue being investigated. The issue being investigated was whether patients epilepsy knowledge had any correlation with their self-management practices. It is well known that uncontrolled epilepsy affects learning ability especially in children (Yang, Hao, Yu, Xu, & Zhang, 2018), which later affects learning ability in adulthood. Therefore, an assessment of how

much a patient's knowledge of the condition influences their health behavior is an integral part of intervention planning.

Comparison being made. A correlation analysis was made between scores on knowledge of epilepsy versus scores on self-management scales.

Outcome. The outcome of this study was expected to show a strong positive correlation between levels of epilepsy knowledge and self-management.

Definition of Key Terms

Epilepsy knowledge. This is what patients know about epilepsy in general as evidenced by their scores in the epilepsy knowledge questionnaire. Literature shows that knowledge of epilepsy helps patients cope with the effects of both seizures and treatment compliance (Malek et al., 2017). However, there are significant misconceptions about epilepsy worldwide and these sometimes-mythical beliefs about epilepsy significantly affect how patients and families approach treatment (World Health Organization, 2014). Poor knowledge has been demonstrated in clinical practice about the causes and consequences of seizures, the purpose or side effects of medication, and what options are available when medications fail to achieve seizure freedom (Pickrell & Smith, 2014).

Treatment adherence. The World Health Organization (2018) defines adherence as the extent to which a person's behavior such as taking medication, following a diet, or executing lifestyle changes, corresponds with agreed recommendations from a health care provider. For this study adherence was limited to medication-taking behavior and assessed in the self-management questionnaire.

Self-management. Self-management is defined as the process of assuming responsibility for one's own behavior and welfare (Oxford Dictionary, n.d). In healthcare, self-management

evolved from the work of Albert Bandura in his development of the self-efficacy concept (Sell, Amella, Mueller, Andrews, & Wachs, 2016). It is described as the daily management of chronic conditions by individuals over the course of illness (Bandura, 2005). For this project, epilepsy self-management scores were compared with epilepsy knowledge scores to determine correlation.

Summary

A wealth of evidence in literature shows that epilepsy has a significant impact on the population in general and not just those diagnosed with epilepsy. It carries serious global and local significance in terms of the effect on quality of human life, costs, both direct and indirect, and a mortality rate that is four times higher in people with epilepsy than the general population. It is therefore vital for healthcare providers to provide the right kind of services and education needed to improve health outcomes for people with epilepsy. Merely dispensing medications and evaluating side effects is not enough to promote adherence and self-management in epilepsy (Malek, Heath, & Green 2017).

As healthcare providers, understanding the education a patient with epilepsy needs and evaluating their self-management behaviors is essential in determining how best to intervene. Multiple studies have shown the lack of or rather poor epilepsy knowledge prevalent among patients, providers, caregivers, teachers and the public in general. Other studies have shown poor self-management and adherence in people with chronic conditions. No studies were available to show whether knowledge and self-management were correlated.

Chapter 2: Theory and Literature Review

The guiding theoretical framework for this project was based on Albert Bandura's Social Cognitive Theory. Bandura (2001), explained that there are core determinants that operate human consciousness and adaptation or learning. These determinants are; intentionality,

forethought, self-regulation, and self-reflectiveness about one's capabilities, quality of functioning, and meaning of one's life pursuits (Bandura, 2001). In the healthcare application of this theory, these core determinants of adaptation are; (a) knowledge of health risk and the benefits of health practices, (b) perceived self-efficacy of control over one's health behavior, (c) expected outcomes of the cost and benefits of various health behaviors, (d) personal health goals and plans to meet them, and (e) the perceived barriers and facilitators to the change one seeks (Bandura, 2005). A diagram of this model is attached with permission from the author as Appendix A.

Self-efficacy, which is at the core of this theory refers to the confidence one has in their ability to control a situation or condition (Bandura, 2001) Those with high levels of self-efficacy are likely to believe in good outcomes, exhibit behavior that overcomes challenges and maintain a behavioral change (Bandura, 2004). The opposite can therefore be assumed true, that those with low self-efficacy will likely not believe in their ability to effect good outcomes and will not exhibit behaviors that maintain an expected change.

This study evaluated one aspect of self-efficacy in patients with epilepsy. This was their knowledge of epilepsy and health practices in the form of self-management. Additionally, the study evaluated whether knowledge correlated with their health practices as evidenced by scores on the Epilepsy Self-Management Scale.

Literature Review and Search Process

Standard systematic review procedures were used to ensure the search was extensive and contained minimal bias. The Cumulative Index of Nursing and Allied health Literature (CINAHL) and PubMed databases were searched through the University's library access. Advanced Google Search and Google Scholar were also utilized extensively. Search terms used

were "Epilepsy Definitions" "Epilepsy Knowledge," "medication adherence," "Self-management" and "Social cognitive theory." Medical Subject Headings (MeSH) terms "Epilepsy" and "Seizures" were used interchangeably for the search. All the search terms were combined in different formats using BOOLEAN operators such as "AND," "NOT" or "OR" as needed to find the relevant articles. Only the articles with the correct combination of search terms were considered for the final review

The inclusion criteria for this search were, (a) articles written within the past five years (2013-2018), (b) peer-reviewed academic journals, (c) research articles, (d) English language, (e) human subjects, (f) full text, and (g) abstract available. Excluded from the search were commentary and editorial type articles. Using the Advanced search option and MeSH terms "Epilepsy" NOT "seizures," 881 articles were found. Combining the terms "Epilepsy Knowledge NOT Seizures" reduced this number down to 91 articles. A visual examination of the titles and a brief review of abstracts yielded one relevant article (Ross, Gilani, & Naidoo, 2015). For this subject, the year of publication limit had to be removed to obtain relevant articles from 1993, detailing the development of an epilepsy knowledge tool (Jarvie, Espie, & Brodie, 1993a; Jarvie, Espie, & Brodie, 1993b). An interlibrary loan had to be completed for these articles.

Similar searches were conducted using search terms "Self-Management AND Epilepsy." The return was 26 articles of which four were found most relevant. Other articles on this subject were found on Google Scholar and Google advanced search options, which yielded several relevant articles from the Public Library of Science One (PLOS One) and ResearchGate the network. The total number of articles synthesized for this project was 32. Quality of the articles was determined using the ranking method based on the work of Melnyk and Fineout-Overholt (2015). A table of the reviewed articles can be found in Appendix B.

Summary of the Literature

Literature review about epilepsy knowledge found some relevant articles that were published before the five-year limit on the search criteria. Most were also conducted in regions outside the United States. In developing a standardized questionnaire to assess epilepsy knowledge, Jarvie, Espie & Brodie (1993) in Europe gathered questions from the main contemporary texts on epilepsy and other existing measures of knowledge. They developed this into a list of true/false questionnaire that assessed both medical and general knowledge of epilepsy. For external validation, the questionnaire draft was sent to a panel of 16 experts in the field of epilepsy. Fourteen of 16 questionnaires were received back from experts ranging from medical sociologists to clinical pharmacist. Experts were asked to give opinions as to whether they believed the answers were correct and if any of the questions were too ambiguous or misrepresented the basic ideas. The questionnaire was then revised according to recommendations and tested on 82 patients with epilepsy in an outpatient clinic. Results showed that the questionnaire had good internal consistency and reliability with a Cronbach's alpha of 0.6256 on the medical knowledge section and 0.4929 for social knowledge. This questionnaire was named Epilepsy Knowledge Profile-General (EKP-1).

A second tool was developed similarly to assess the patient's knowledge of their own condition and labeled EKP-2 (Jarvie et al., 1993b). Both tools have been adapted and used in different studies depending on the population being studied. In some studies, components of the EKP-1 and EKP-2 were adapted to make the EKP-questionnaire (EKP-Q) (Peterson et al., 2017). For this proposed study, the EKP-Q was used as adapted by the Royal College of Australian General Practitioners (Peterson et al., 2017). A copy of this tool can be found in Appendix C.

Healthcare professionals were assessed for knowledge about epilepsy in a study conducted in Sao Paulo Brazil by Vancini et al., (2012). In this cross-sectional study, healthcare professionals with academic degrees in physical education (n=134), nutrition (n=116), medicine (n=100), psychology (n=53), nursing (n=122) and physiotherapy (n=99) were given a 25-question adaptation of the epilepsy knowledge profile. In total, 624 participants were assessed, 88.5 % had a post-graduate education, and the other 11.5% had undergraduate degrees only. Scores ranged from 0-10 with very good being (10.0–8.0), good (7.9–6.0), regular (5.9–4.0), bad (3.9–2.0), and very bad (1.9–0.0). Results showed that physicians obtained the highest scores (mean of 7.2 ± 1.1) followed by nurses 6.3 ± 1.2 . These scores were significantly different compared to nutritionists whose scores were 5.2 ± 1.5 and physical education whose scores were 4.9 ± 1.5 . Altogether, these scores were not very good considering these were healthcare professionals. None of the health professional's category in the study had the "very good" scores of 10.0-8.0. These findings reflected other studies showing insufficient knowledge about epilepsy among professionals of various types.

A study conducted at an outpatient epilepsy care center in Lithuania set out to assess, (a) knowledge of disease among people with epilepsy, (b) estimate differences in disease knowledge, and (c) evaluated how epilepsy influenced patients' daily lives. Tools used for the study were an adaptation of the EKP-1 and 2 questionnaires, the Hospital Anxiety and Depression scale (HAD) and a modified quality of life questionnaire. One hundred and thirty-four of the 211 participants completed the questionnaires. According to the HAD scale, 50.4 % of patients acknowledged symptoms of anxiety while 33% indicated symptoms of depression. As for epilepsy knowledge, 43% could not identify their seizure types or etiologies, 20% knew the results of their neuroimaging studies, and only 3% knew the results of their

electroencephalogram (EEG). However, 80% of patients in this study knew the names or their antiseizure medications and 91% knew the dose and frequency of their drug regimen (Mameniskiene, Sakalauskaite-Juodeikiene, & Budrys, 2015).

Jones, Atkinson, Cross, & Reilly (2018) did a systematic review of research focused on the knowledge and attitudes towards epilepsy among teachers. The review included 44 studies ranging from cross-sectional surveys to interventional studies pooling a total of 17,256 participants in 27 different countries. Few studies employed valid and reliable instruments, and therefore it was not possible to systematically analyze the levels of epilepsy knowledge. Thematic analysis, however, showed that (a) deficits in knowledge and negative attitudes were pervasive across all studies, (b) teachers often had negative attitudes towards the participation of children with epilepsy in sports, and (c) teachers often expressed limited knowledge of seizure management and emergency procedures.

Dinta, Meena, Achal, & Mamta, (2017) compared epilepsy knowledge among caregivers of people with epilepsy and the general public's knowledge of epilepsy. In this study, they used a descriptive cross-sectional survey administered to 200 participants. One hundred were caregivers who visited the outpatient epilepsy clinic and 100 general public participants who visit other outpatient departments in India Institute of medical sciences clinics. The questionnaires used were an adaptation of the epilepsy knowledge and first aid questionnaire along with a demographics form. Results showed that knowledge regarding first aid management of seizures was deficient and almost the same among caregivers and the general public. Scores on this measure for both were 6.53 ± 2.21 for caregivers and 6.11 ± 1.96 for the general public. Epilepsy knowledge scores were also poor at 7.19 with a standard deviation of 2.69 and 2.65 respectively.

With many studies showing insufficient knowledge about epilepsy and its management, the epilepsy foundation supported by the Centers for Disease Control and Prevention began public awareness campaigns to address this lack of understanding that worsened the challenges people with epilepsy face daily. In their report, they listed activities such a multifaceted public education and awareness campaigns designed to reach broad populations, minority groups such as Spanish speaking people and people with epilepsy. The campaign channels included traditional media such as radio, television and newspapers, social media, community opinion leaders and celebrity spokespersons. Outcomes of these campaigns over a period of ten years showed significant results. There was increased demand for information on epilepsy and seizures, increased visits to the Epilepsy Foundation's webpages, increased interest in issues surrounding epilepsy and discussions generated through the social media and celebrity endorsements. Support from medical experts also increased along with attendance at educational events (Price, Kobau, Buelow, Austin, & Lowenberg, 2015).

For studies that sought to evaluate self-management in epilepsy, most used the Epilepsy Self-Management Scale (ESMS) and adaptations of quality of life questionnaires. The ESMS data found was based on the work of Colleen DiIorio (2010) who developed the scale in conjunction with the Managing Epilepsy Well network (MEW). A newer scale was developed in 2015 and named the Adult Epilepsy Self-Management Measurement Instrument (AESMMI), in which Colleen DiIorio, Ph.D., was the main collaborator (Escoffery et al., 2015). Both scales were tested for internal validity, reliability, and test-retest reliability during development (DiIorio, 2010; Escoffery et al., 2015). For this study, AESMMI was used and a copy of the tool can be found in Appendix F with permission (Appendix E) from the author.

A concept analysis of self-management in community-dwelling older adults with multiple chronic conditions was conducted by Garnett, Ploeg, Markle-Reid, & Strachan (2018). In this analysis, 30 articles were pooled from a systematic review of the literature to examine how the concept of self-management is applied to different chronic conditions in various settings. At its conclusion, the study defined self-management as, (a) the process of using financial resources to manage chronic disease, (b) acquiring health-related and disease-related education from health professionals, (c) receiving a variety of ongoing social support, (d) responding in positive ways to variations in health status, (e) continuing to engage with the health system and actively participating in sustained disease monitoring and management.

Self-management challenges faced by adults with epilepsy are numerous, and range from the limited understanding of the condition and its treatments, psychosocial issues, to lack of integration into their communities (Fraser et al., 2010). In a randomized controlled trial evaluating self-management interventions for adults with epilepsy, Fraser et al., (2015) implemented the Program for Active Consumer Engagement in Self-Management (PACES) as the intervention for patients with epilepsy. Eighty-three participants with chronic epilepsy were recruited from two epilepsy care centers in Seattle Washington. They were assigned randomly to the intervention group or the treatment as usual group. The intervention involved a six to eight-week program administered to groups of six to eight adults during a meeting that lasted about 75-minutes. The meetings were facilitated by a psychologist and a trained peer with epilepsy. Self-management aspects of epilepsy were discussed during these meetings. Results showed statistically significant improvements in Epilepsy Self-Management Scale ($p=0.001$) and Quality of Life in Epilepsy scale ($p=0.002$) compared to the control group (Fraser et al., 2015). Other secondary outcomes had significant improvements also.

A systematic review of group self-management interventions was conducted by Smith, McKinlay, Wojewodka, & Ridsdale, (2017). In this review, only studies that involved face to face interventions for adults with epilepsy were included. The studies had to have been published between the years 1995 and 2015. Only 11 studies met this criterion, nine of which were randomized controlled trials. All the studies included focused on the effects of group education interventions for people with epilepsy, especially poorly controlled epilepsy. Statistically significant improvements were shown after interventions in the various measures used to assess outcome. The most common measure was the quality of life scale, epilepsy self-efficacy scale, and epilepsy self-management scale. Due to the heterogeneity of the studies, it was not possible to conduct a statistical meta-analysis.

Studies examining treatment adherence were also reviewed. The most significant one was a systematic review of adherence in people with epilepsy by Malek, Heath, and Greene (2017). In this review, they set out to determine the prevalence of non-adherence to antiseizure medications, evaluate whether specific clinical and demographic features could allow the providers to identify those at highest risk and identify the techniques that can be used to improve adherence. Seventeen articles were systematically reviewed. Findings reported significant medication non-adherence to be between 26% and 79% the large variance was partly due to the heterogeneity of the populations. This also reflected differences in what clinically significant medication non-adherence was. Educating patients and their caregivers about the risks associated with poor adherence, certain behavioral interventions, and simplifying their drug regimens were shown to improve adherence.

Another systematic review of 154 articles examined the relationship between patient empowerment and adherence. In this article Náfrádi, Nakamoto, & Schulz, (2017) found that

there was a strong positive relationship between medication adherence and self-efficacy. They also found that patient empowerment improved other outcomes assessed such as disease management and knowledge acquisition. However, for patient empowerment to work, the article suggested that it required a shared sense of control between the provider and patient where both parties collaborated and continuously negotiated during medical encounters.

Synthesis of the Literature

Epilepsy knowledge. The populations studied to assess knowledge included caregivers (Dinta, Meena, Achal, & Mamta, 2017), people with epilepsy (Doughty, Baker, Jacoby, & Lavaud, 2003; Mameniskiene, Sakalauskaite-Juodeikiene, & Budrys, 2015; Peterson et al., 2017; Ross et al., 2015), teachers (Jones, Atkinson, Cross, & Reilly, 2018), and healthcare professionals (Vancini et al., 2012). Numerous studies reported poor knowledge of epilepsy among the various groups (Dinta Suresh et al., 2017; Peterson et al., 2017; Price, Kobau, Buelow, Austin, & Lowenberg, 2015; Ross et al., 2015) and lack of satisfaction with the type of education received (Doughty et al., 2003). A report from the national epilepsy foundation public awareness campaigns in 2001-2013 also reported that the poor understanding of epilepsy among the general public possibly magnified the challenges faced by those who lived with epilepsy. These challenges included limited treatment opportunities, exclusion from full participation in daily life activities, physical restraint, social exclusion and other adverse outcomes related to poor first aid responses (Price et al., 2015).

Much of the epilepsy education patients received in the studies reviewed, was given by the healthcare providers during clinic visits. In most cases, the education was in the form of verbal instruction or simple brochures and pamphlets. There were the usual time constraints involved with such clinic visits and therefore, it was rare for the providers and patients to have a

formal evaluation of whether the patient's educational needs and the education being provided corresponded. Other epilepsy education was often self-sought by patients through online media and support group participation sponsored by local epilepsy groups (Doughty et al., 2003). The Epilepsy Foundation reported hosting training programs for teachers and school personnel on managing students with epilepsy once a year before the school year begins (Epilepsy Foundation, 2018).

Studies that have used the EKP-Q were designed as cross-sectional surveys of different populations (Dinta et al., 2017; Mameniskiene et al., 2015; Peterson et al., 2017; Ross et al., 2015; Vancini et al., 2012). There was one systematic review of 54 other cross-sectional studies about teachers' knowledge and attitudes towards epilepsy (Jones et al., 2018). All the studies reported significant deficits in knowledge of both the medical aspects of epilepsy and knowledge of one's own condition in general (Peterson et al., 2017; Ross et al., 2015; Vancini et al., 2012). In some of the studies, every third client who presented to the epilepsy treatment centers was recruited to reduce selection bias (Ross et al., 2015), while in other studies, the questionnaire was administered to everyone who consented and met their inclusion criteria of having epilepsy or being a caregiver who was able to read and understand English (Peterson et al., 2017; Vancini et al., 2012).

Self-management. Self-management has been applied to different chronic conditions in disease-specific ways such as epilepsy self-management, diabetes self-management and arthritis self-management (Garnett, Ploeg, Markle-Reid, & Strachan, 2018). The need for epilepsy self-management education was apparent in all the nine articles reviewed. There were three randomized controlled clinical trials (Fraser et al., 2015; Leenen et al., 2018; Magill et al., 2015), three systematic reviews of several other self-management programs (Begley et al., 2018;

Edward, Cook, Giandinoto, & Jo-Ann, 2015; Smith et al., 2017), two cross-sectional studies (Fraser et al., 2010 ; DiIorio, 2010) and one systematic data analysis to develop a self-management instrument (Escoffery et al., 2015).

Fraser et al. (2010) discussed the need for epilepsy self-management programs as vast compared to the available programs for other chronic conditions such as diabetes. The few available programs such as the Program for Active Consumer Engagement in Self-Management (PACES) in the USA, the Modular Service Package for Epilepsy (MOSES) in Germany and Sepulveda Epilepsy Education (SEE) in the USA were not consistently being utilized (Smith et al., 2017). A systematic review of the benefits of self-management interventions for adults with epilepsy showed that such programs improved knowledge, self-confidence, and quality of life for people with epilepsy and recommended the inclusion of such programs in the comprehensive care of people with epilepsy (Edward et al., 2015). Another systematic review showed significant improvements in self-management outcomes and a preference for programs that involved face to face individual or group meetings led by an epilepsy professional (Fraser et al., 2010). The epilepsy self-management programs in the literature involved two-day education or several timed meetings over several weeks for people with epilepsy. All were conducted by a medical facilitator and a trained person with epilepsy. Other studies such as Self -Management Education for Adults with poorly controlled Epilepsy (SMILE-UK) and the ZMILE study in Norway showed similar results regarding improvement in the self-management scores following the program intervention (Leenen et al., 2018; Magill et al., 2015). PACES is now offered as a packaged module program for implementation at epilepsy centers by the managing epilepsy well network (Sajatovic et al., 2016).

Web-based programs were also mentioned in the literature. An example is the Managing Epilepsy Well Network (MEWN) and WebEase, an internet-based, theory-driven, self-management program for adults with epilepsy (DiIorio et al., 2009). There were no systematic reviews for the web-based programs. However, the evaluation of WebEase reported that participants had higher levels of self-efficacy and social support following completion of the program. There were significant improvements in the pre and post-test scores in epilepsy self-management ($p = 0.015$), improved medication adherence ($P = 0.002$) and sleep quality ($p = 0.007$) (DiIorio et al., 2009).

Treatment adherence. The 2003 World Health Organization (WHO) report on medication adherence reported that increasing adherence interventions might have a far more significant impact on the health of a population than any improvement in a specific medical treatment (WHO, 2018). This was affirmed in epilepsy especially for those who remain uncontrolled despite being on antiseizure medications (Malek et al., 2017). In many cases, poorly controlled epilepsy is related to poor treatment adherence (Leenen et al., 2018), and an assessment of adherence is therefore crucial to providing adequate care by the clinicians. The availability of many new anti-seizure medications on the market only adds to the confusion among patients about options available to them and what advice they should follow (Brodie, 2010). This confusion is mentioned in the literature as intelligent non-adherence, referring to patients' intentional non-adherence based on reasons, such as perceived misdiagnosis, misinformation or side-effects caused by medications (Náfrádi et al., 2016).

Six articles were reviewed concerning treatment adherence. Three systematic reviews (Malek et al., 2017; Náfrádi, Nakamoto, & Schulz, 2017; Yang et al., 2018), two cross-sectional

studies (Moura et al., 2016; Náfrádi et al., 2016), and one expert report from the Mayo clinic proceedings (Brown & Bussell, 2011).

Factors affecting adherence found in the literature included; lack of understanding of their disease (Malek et al., 2017), lack of involvement in the treatment decision-making process, and poor health literacy (Brown & Bussell, 2011). Provider-related factors included, failure to explain the benefits and side effects of a medication adequately (Brown & Bussell, 2011; Moura et al., 2016), inadequately considering the financial burden to the patient (Brown & Bussell, 2011), and ineffective communication between the specialists and primary care providers, especially in patients with other chronic diseases (Dalic & Cook, 2016; Moura et al., 2016; Yang et al., 2018).

High self-efficacy and internal locus of control were consistently found to promote medication adherence (Náfrádi et al., 2017; Náfrádi et al., 2016). Patient education was found to be an important factor in promoting adherence especially formal education programs such as the diabetes self-management programs (Brown & Bussell, 2011). Merely addressing medication side effects at every clinic visit for people with epilepsy did not appear to increase patient-reported medication adherence (Moura et al., 2016).

Summary

This review showed that knowledge of epilepsy remains poor across different populations. This was worse in people with uncontrolled epilepsy than among caregivers, teachers, and clinicians. Patients with higher education levels scored better on the various knowledge questionnaires than those with a lower level of education (Mameniskiene et al., 2015). Cultural beliefs and stigma about the condition also negatively affected the information exchanged in communities about epilepsy (Doughty et al., 2003; Ross et al., 2015), therefore

limiting the information people with epilepsy received. It was also shown that the education that patients receive from clinicians is rarely adequate or remembered by the patients (Malek et al., 2017).

Self-management was shown in the literature to improve significantly when the appropriate knowledge of epilepsy was given (Edward et al., 2015; Price et al., 2015). Recommendations for formal self-management programs were repeated numerous times in the studies and a positive correlation seemed to be evident between levels of knowledge and self-management.

Medication adherence in many studies was evaluated as a part of the self-management questionnaire. Several reports showed that good self-management promoted medication adherence, and therefore, emphasis should be placed on promoting self-management and not merely promote medication adherence (Brown & Bussell, 2011; World Health Organization, 2018)

Chapter 3: Methodology

Chapter three of this quality improvement study described the research design and methods that were used to evaluate the correlation between knowledge and self-management practices in patients with epilepsy. The rationale for choosing the research design is discussed along with a detailed discussion of the data collection, data handling, data processing and how records were secured. Ethical issues of assuring patient anonymity are also addressed and methods to eliminate potential bias reported.

Research Design

The study design was a cross-sectional, descriptive correlation, quantitative study. According to Polit and Beck (2004), a quantitative study is one that seeks to describe phenomena

by gathering numerical data using polls, questionnaires or surveys and objectively applying statistical measurements to analyze the data. The goal of a quantitative descriptive study is to determine an association between two variables (Polit & Beck, 2004). Cross-sectional studies usually involve data collection at one point in time. Variables are usually measured once as opposed to the quantitative experimental studies in which variables are measured before and after an intervention. In the proposed study, participants were given two questionnaires that assessed the variables self- management and epilepsy knowledge. This design is efficient for collecting massive amounts of data about a problem and therefore great for solving practical problems (Polit & Beck 2004).

The rationale for choosing this research design is that cross-sectional designs are less time consuming and involve minimal contact with subjects. This reduces the chances of missed opportunities or missing data related to subject drop out or failure to follow through. The tools used in this study have been tested for validity and reliability therefore, reducing bias. Content validity index for the AESMMI tool was 89.9% and interrater coefficient alpha of 0.953 (Escoffery et al., 2017). The Cronbach's alpha score for the EKP-G questionnaire was 0.6256 (Jarvie, Espie, & Brodie, 1993a). The only disadvantage for this study method is that it requires a large sample size for the data to be considered generalizable.

Instruments

The Epilepsy Knowledge Profile Questionnaire (EKP-Q) and the Adult Epilepsy Self-Management Measurement Instrument (AESMMI) were used for this study. Both tools can be found in Appendix C and E. Besides showing good validity and reliability during development. These tools were also peer-reviewed by experts in their respective fields (Escoffery et al., 2015; Peterson et al., 2017). The original EKP-Q questionnaire contained 55 items that measured both

medical and social knowledge of epilepsy (Jarvie, Espie, & Brodie, 1993a; Jarvie, Espie, & Brodie, 1993b). Several studies that have used the EKP-Q have adapted different items in the original questionnaire to fit the population being studied. For this study, the 20-item questionnaire was used as adapted by the Royal College of Australian General Practitioners (Peterson et al., 2017). The reliability and validity data for this adapted tool was not available at the time of this study. The tool required simple true/false responses from the participants. Scores ranged from 0 to 20 with a higher score indicating that the participant has more knowledge of epilepsy in general. Texas Woman's University's statistician recommended that an option for "I don't know" be added to the true/false responses for the data to distribute under the bell curve during analysis evenly.

Self-management was measured using the AESMMI which is a 65-item scale that assesses the frequency of using epilepsy self-management practices (Escoffery et al., 2015a). Each item is rated on a five-point Likert scale of frequency (i.e., 1=never to 5=always). The instrument's items are grouped to assess 11 discrete factors: 1) healthcare communication, 2) treatment management, 3) coping, 4) social support, 5) seizure tracking, 6) wellness, 7) seizure response, 8) safety, 9) medication adherence, 10) stress management, and 11) proactivity (Escoffery et al., 2015b). Overall, higher scores will indicate that the subject is more likely to engage in epilepsy self-management behaviors.

Sample

Purposeful sampling was used to obtain the study sample for this project. The goal of purposeful sampling was to find subjects that have both knowledge and experience with the phenomenon being studied (Polit & Beck, 2004), in this case, people with epilepsy. The inclusion/exclusion criteria for this study was used as a screening tool to identify eligible

patients. Recruitment was done at an outpatient neurology clinic in Dallas that has 15 neurologists and four advanced practice nurses as providers. Patients come from North Dallas and Southern Oklahoma.

The inclusion criteria were; a) adult patients 18 years and older, b) diagnosed with epilepsy, c) prescribed at least one antiseizure medication, d) able to speak and read English, e) living in the community, and f) willing to complete the questionnaires. The exclusion criteria were; a) cognitive impairment related to medical problems and b) people in hospitals or nursing homes where care self-management is not applicable.

Only adult patients with epilepsy were considered for this study because this was the population readily available to the investigator and of interest. Both instruments used required that the subjects be able to practice most of the measures and had independence with decision-making, which excluded children or cognitively impaired individuals. The inclusion of at least one antiseizure medication prescription was necessary because part of the self-management questions included medication adherence and how patients dealt with side effects. The ability to read and understand English was necessary for successful data collection.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion criteria
Age 18 and older	Cognitive impairment
Diagnosed with epilepsy	Inability to read or speak English
Taking at least one antiseizure medication	
Speaks and reads English	
Live independently in the community	

Sample Size

According to Moinester and Gottfried (2014), an adequate sample size for a correlation study is dependent on the analysis planned and confidence interval desired. An a priori power analysis was conducted using G*Power 3.1.9 to determine the minimum sample size required to find statistical significance using Pearson's correlation analysis. With a desired level of power set at .80, an alpha (α) level at .05, and a moderate effect size of .30 (ρ), it was determined that a minimum of 84 participants would be required to ensure adequate power. However, with a moderate to large effect size ($\rho = .40$), a sample of 46 participants would be required (Cohen, 1988). The study obtained about 35 participants due to the time constraints for data collection and processing. According to Polit and Beck (2004), sample sizes can be smaller if there is reason to believe that the variables being studied will be strongly related. The hypothesis for this study assumed that a strong correlation was present between epilepsy knowledge and epilepsy self-management.

Ethics and Human Subjects Protection

The study proposal was presented to the Institutional Review Board (IRB) chair at Texas Woman's University for an IRB exemption request. This was based on the fact that it met the requirement that the participants should not be identifiable, and any disclosure of the responses could not reasonably place the participants at risk. The exemption required that the sentence, "The return of your completed questionnaire constitutes your informed consent to act as a participant in this research," to be placed at the top of the questionnaires used in lieu of consent forms.

The response from the IRB chair considered this to be a class project and a Quality Improvement study whose findings were not going to be published as generalizable knowledge

and therefore, did not require an IRB review. A copy of the protocol number and approval notice can be found in Appendix G.

Recruitment and Site

Participants were recruited for the study from January 1, 2019, to February 13, 2019. This was accomplished via email invitations to patients with epilepsy seen at an outpatient neurology clinic in Dallas using a PsychData link (Appendix J). The invitation email introduced the purpose of the survey and asked patients to click on the link if they were willing to participate. Once patients logged into the link, they were reminded that participation was voluntary, and a return of the survey constituted their informed consent. No identifiable patient information was collected. Data from the survey responses was collected into the PsychData account and handled only by the author and statistician.

Summary

Due to the time constraints for data collection during this study, a cross-sectional design was chosen because participants could be assessed in one event. This made the collection of data easier, as a follow-up visit was not required to get the questionnaires back. The sample size was considered sufficient to start processing once 30 respondents had returned the questionnaires. Privacy of the information was ensured by excluding identifiable patient information in the demographics form and securing all responses to the survey went into a single password-protected account on PsychData.

Chapter 4: Results and Outcomes

The Study Question

Correlation studies require a hypothesis and a null hypothesis (Pallant, 2016). The hypothesis for this study sought to find out whether there will be a correlation between epilepsy

knowledge and self-management practices in patients with epilepsy. The null hypothesis was therefore; There is no correlation between epilepsy knowledge and epilepsy self-management behaviors.

The study question was; In adult patients with epilepsy, does the level of epilepsy knowledge correlate with their self-management practices?

Implementation of the Study

Phase 1 - Approval of the study. On September 25, 2018, the author discussed the project with the neurology clinic in Dallas, Texas where the participants were to be recruited. Permission was granted to conduct the study (Appendix I). On October 9, 2018, the project proposal was submitted to the project coordinator for the Texas Woman's University Institutional Review Board (IRB) where it was determined that the study fell under the category of a class project, and therefore did not need full IRB review (Appendix H). The proposal was defended successfully to the Doctor of Nursing Practice (DNP) scholarly project committee on November 20, 2018, and the proposed changes to the literature review were completed following the defense.

Phase 2 - Data collection. One hundred and twenty email invitations were sent out to patients that were diagnosed with epilepsy and met the inclusion criteria. Most of the patients were notified prior to receiving the invitation, during regular office visits that they would be receiving an email with epilepsy knowledge and self-management questions sometime around January of 2019.

A week after the initial email invitations containing the link to the survey were sent out, only 17 responses were received, with some patients having completed only the first half of the survey. A second invitation with a link to the survey was sent out. This second email thanked

everyone for completing the survey and asked those that were still considering completing the survey to do so within the following week. Ten more responses were received within the following few days. The Epilepsy Foundation of Texas was asked for help to invite more people into the survey. Their director agreed to disseminate the survey to their email contacts that were diagnosed with epilepsy and met the inclusion criteria. This improved responses to 39 participants in total. During the analysis of data, only 35 responses were correctly completed with valid data that could be analyzed. Thirty-five of the respondents completed the knowledge questionnaire (EKP-Q) and demographics section while 29 completed all the sections of the survey.

Phase 3 – Data preparation. Raw data from the responses were put into SPSS by the author. Coding of the data was required to convert the demographics information into a format SPSS could process. For example, marital status was assigned the number 1 for single, 2 for being in a steady relationship, 3 for married, 4 for remarried, 5 for divorced, and 6 for widowed. Gender was designated 1 for female, 2 for male and 3 for other. Age did not require modification as this was expressed numerically. Level of education was converted to; 1 for elementary, 2 for some high school, 3 for completed high school, 4 for some college, 5 for completed undergraduate, and 6 for postgraduate.

Data from the EKP-Q questionnaire and AESMMI were already in a format compatible with SPSS and therefore did not require as much re-coding. The true/false statements from the EKP-Q were assigned; 1 for “True”, 2 for “False”, and 3 for the “I don’t know” responses. For analysis on SPSS, this had to be re-coded to 1 for correct answers and 0 for incorrect and “I don’t know” responses. Likert scale responses from the AESMMI-65 were assigned; 1 for “Never”, 2 for “Rarely”, 3 for “Sometimes”, 4 for “Often”, and 5 for “Always”. Reverse coding was

required for questions 15, 16, 18, 19, 21, 22, and 54 because they were negatively worded. For example, “When my seizure medicine is running out, I stop taking it.” The high score for this question would be never, so we had to recode “Never” as 5 instead of the usual “1” in the positively worded questions.

Working with the statistician from the university, data from the survey were organized, checked for outliers and missing responses, then reviewed for errors, before analysis. A total of 39 responses were available for analysis. Four had missing data on both the EKP-Q and AESSMI questionnaires and were therefore invalid. Thirty-five completed the EKP-Q and AESSMI but 29 of them had missing data on the AESSMI questionnaire.

Descriptive statistics were completed first to describe the respondents. This was necessary to analyze the demographics of the respondents. The analysis provided information such as mean and standard deviation in the categories such as ages, percentages of males versus female participants, the range of scores, and data distribution on a frequency curve.

Phase 4 - Defend the scholarly project. In March of 2019, the author will defend the DNP scholarly project to the DNP scholarly project committee. Changes to the report of the intervention will be determined. In April of 2019, this author will present the quality improvement study to the Texas Woman’s University (TWU) Graduate Student Research Symposium in a poster presentation. The study will also be presented to the staff at the neurology clinic that provided participants for this study.

Descriptive Statistics Results

Demographic data for this study included age, race, gender, marital status, level of education, work status, living situation, years of epilepsy diagnosis and frequency of seizures. Ages of participants ranged from 21 the youngest to 72 for the oldest participant. The average

age was 45.51 with a standard deviation of 14.3. Forty percent of the participants were male (n=14), and 60% were female (n=21).

Table 2

Age

	N	Lowest	Highest	Mean	Std. Deviation
Please enter your age.	35	21	72	45.51	14.267
Valid N	35				

Marital status was divided into seven categories, but only four were represented in the respondents. Sixty eight percent of participants were married (n=24), 17.1% were single (n=6), 5.7% were separated (n=2), and 8.6% were divorced (n=3).

Table 3

What is your marital status?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	Single	6	17.1	17.1	17.1
	Married	24	68.6	68.6	85.7
	Separated	2	5.7	5.7	91.4
	Divorced	3	8.6	8.6	100.0
	Total	35	100.0	100.0	

Race was divided into seven categories including White (Caucasian), Black (African American), Hispanic (Latino), Asian, Indian (Native American), Mixed, and Other (Declines to Specify). Most participants were White (82.9%) followed by African American (8.6%) and Hispanic 5.7%. Only one person identifies as “other” making the final 2.9%.

Table 4

What race do you identify with?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	Black (African American)	3	8.6	8.6	8.6
	White (Caucasian)	29	82.9	82.9	91.4
	Hispanic (Latino)	2	5.7	5.7	97.1
	Other	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

Level of education for the respondents ranged from high school education to doctoral degrees. The majority had undergraduate degrees and master's degrees (25.7%) each, while high school degrees and some college education ranked at 17.1% each. Doctoral degrees and "other" category ranked 5.7% and 8.7% respectively.

Table 6

What is your highest level of education?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	High school graduate	6	17.1	17.1	17.1
	Some college	6	17.1	17.1	34.3
	Undergraduate degree	9	25.7	25.7	60.0
	Master's degree	9	25.7	25.7	85.7
	Doctoral degree	2	5.7	5.7	91.4
	Other (please specify)	3	8.6	8.6	100.0
	Total	35	100.0	100.0	

Work status category was also reported. Most respondents were employed (45.7%), followed by 17.1% unemployed, 14.3% retired, 14.3% disabled and 8.6% self-employed. Their living

situations ranged from living with a spouse (74.3%) to living alone (14.3%) and living with parents (11.4%).

Table 7

What is your work status?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	Unemployed	6	17.1	17.1	17.1
	Employed	16	45.7	45.7	62.9
	Self-employed	3	8.6	8.6	71.4
	Retired	5	14.3	14.3	85.7
	Disabled	5	14.3	14.3	100.0
	Total	35	100.0	100.0	

Table 8

What is your living situation?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	Alone	5	14.3	14.3	14.3
	With parents	4	11.4	11.4	25.7
	With spouse or partner	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

Years of epilepsy diagnosis ranged from zero to two years to over 10 years with the highest frequency being those that had the diagnosis zero to two years (14.3%). Most

respondents reported experiencing 1-5 seizures a year (42.9%) while 25.7% reported having more than ten seizures a year. Some had controlled seizures (22.9%), and a small percentage had five to ten seizures a year (8.9%).

Table 9

How long have you been diagnosed with epilepsy or seizures?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	0-2 years	5	14.3	14.3	14.3
	3-5 years	4	11.4	11.4	25.7
	5-10 years	3	8.6	8.6	34.3
	10-15years	2	5.7	5.7	40.0
	over 15 years	21	60.0	60.0	100.0
	Total	35	100.0	100.0	

Table 10

About how many seizures do you have in a year?

		Frequency	Percent	Valid Percent	Cum. Percent
Valid	None	8	22.9	22.9	22.9
	1-5	15	42.9	42.9	65.7
	5-10	3	8.6	8.6	74.3
	more than 10	9	25.7	25.7	100.0
	Total	35	100.0	100.0	

Once the demographics of the respondents were reviewed, the inclusion criteria had to be adjusted. The survey automatically eliminated people that did not have epilepsy, but the total number of respondents was so low that requiring respondents to have been diagnosed with

epilepsy for a period of over five years would have brought the total to 26. The study had a target of 30 to 50 patients, so it was decided to allow for this adjustment to the inclusion criteria.

Correlation Analysis Results

Correlation statistics were completed following the descriptive statistics in the form of a bivariate regression analysis. For a simple bivariate regression to be completed, all the questions on the EKP-Q questionnaire (n=20) were re-coded into a single variable by computing the mean of the individual scores. Questions on the AESMMI (n=65) were also re-coded to a single variable in the same manner. A weak ($r=0.378$) but significant ($p=0.05$) positive correlation was found between the variables epilepsy knowledge and epilepsy self-management as shown in the following table.

Table 11

Correlations

		Self-management	Knowledge
Self-management	Pearson Correlation	1	.378*
	Sig. (2-tailed)		.043
	N	29	29
Knowledge	Pearson Correlation	.378*	1
	Sig. (2-tailed)	.043	
	N	29	35

*. Correlation is significant at the 0.05 level (2-tailed).

Expected versus actual outcomes. For this study, a strong positive correlation was expected between the variables knowledge and self- management. This was not confirmed in the results. The reason for this may have been the sample size as discussed in the limitation of the

study section. It was interesting however to note that a few respondents scored high on the knowledge questions and very poorly on the self-management questions as shown in the graph Appendix K.

Quality Indicators and Resources

Valuable resources for this project were my faculty chairs Dr. Haley and Dr. Chrostowski who guided and edited the project as it developed. The statistician from TWU research department was also valuable in designing and analyzing the data. This statistician guided the survey construction on PsychData to ensure quality data would be collected in a relevant manner. He also assisted with the wording of the demographics data so that responses were mutually exclusive and would remove people without epilepsy. Much of the work of preparing the data and analysis was guided by the statistician who ensured the results were accurate and computations were done correctly to answer the study question.

Barriers

A significant barrier to the success of this project was poor response numbers. It required several email invitations to be sent out, along with reminders for participants to return the surveys. Time constraints were another limiting factor as the data needed to be analyzed within a few weeks of sending out the surveys. However, the survey is left open on PsychData and future studies can be done from the data being collected.

Summary

Despite the barriers, the research question in this study was addressed using statistical methods and analysis. It was established that there was a positive correlation between epilepsy knowledge and epilepsy self-management which supported the hypothesis. Ethical issues and challenges of the study implementation were discussed, and resolutions discussed.

Chapter 5: Discussion

Interpretation of Findings

The Pearson correlation coefficient for EKP_Q and AESMMI was $r=0.378$ with a p -value of 0.05. This was weakly positive but statistically significant. According to Pallant (2016), the Pearson correlation coefficient is usually reported as a value between -1 to +1. A value of minus one meant that there is a negative correlation between the two variables, i.e., as one variable score rose, the other score dropped. A positive correlation meant that as one value rose, the other also rose. A zero result would have indicated that there was no correlation between the two variables (Pallant, 2016). The strength of the correlation was inferred by how close to the value +1 the coefficient was. A value of 0.95 for instance, would have indicated a strong positive correlation, while a value of 0.5 would have indicated neutral but positive correlation. The computed value for this study $r= 0.378$ was therefore considered weak but positive.

The results of this study appeared to reflect the findings of Begley et al., (2018) that examined correlates of epilepsy self-management from a database of 436 people with epilepsy. In that study, positive correlations were found among several domains of the self-management questionnaire used. For instance, higher safety management scores were associated with more education and better quality of life while lower information management scores (knowledge) were associated with being male and non-white. Being female was associated with higher information management scores also. (Begley et al., 2018).

The weak correlation found between epilepsy knowledge and epilepsy self-management may have been due to the demographics of the respondents. It appeared that many respondents completed the knowledge questionnaire carefully but were less careful with the self-management questions as many of this section's responses had missing data. Because the study was completed

online and in the privacy of their home, we did not have the benefit of the Hawthorne Effect where people are thought to do better in a study when they believe they are being observed.

Other epilepsy self-management programs such as Program for Active Consumer Engagement in Self- management (PACES) in the United States (Fraser et al. (2015) and The Modular Service Package Epilepsy (MOSES) in Europe (Ried, Specht, Thorbecke, Goecke, & Wohlfarth, 2001) have shown that people with epilepsy needed both knowledge deficits addressed, and self-management barriers addressed for improvement in epilepsy management to occur. Both programs involve education modules given to people with epilepsy over several short weekly sessions by an epilepsy trained professional and in some cases a peer with epilepsy. The face to face sessions also served to address patient questions and concerns while providing a supportive environment for people with epilepsy to learn.

Limitations

Limitations of the study included the fact that this was a cross-sectional survey sent via email. The reliability of self- reported responses could not be ascertained, and many patients seen at the clinic did not have correct email addresses on file. The study required that participants complete the survey to the best of their knowledge, but this did not preclude one from researching the answers to the knowledge questions.

Another limitation of the study was the small sample size. An a priori power analysis recommended 84 participants be recruited for the study. This was not possible with the time limitation and the number of viable emails available to the author. One hundred and fifty email invitations were sent out with reminders to complete the survey sent out a week following the initial invitation. Only 35 participants completed the survey correctly with 29 of them completing only the first questionnaire EKP-Q.

Generalizability was also a limitation of this study as the sample was recruited from only one outpatient clinic in a large metropolitan city. The sample was not representative of adult epilepsy patients as their knowledge and self-management practices may differ from other people with epilepsy living in rural areas.

Recommendations

Future studies of this type should consider using extended time frames in which to collect data. A multicenter involvement with different patient populations such as rural versus urban would be beneficial for data analysis. Future education programs based on similar studies can be done through telemedicine and administered in a manner valued by the patients in the comfort of their homes.

The data collected in the survey could be used for more complex multiple regression analyses. For instance, whether there is a correlation between being female or male and their corresponding self-management scores. Begley et. al (2018) found a positive correlation with females having a stronger correlation with self-management than males. Another interesting correlation to be evaluated in the future is whether the amount of time someone has epilepsy had any relationship with how well they did on self-management scores. However, the research question for this study only focused on whether there was a correlation between epilepsy knowledge and self-management behaviors.

Conclusions

In multiple published studies, as was discussed in the literature review, people with epilepsy were shown to have poor knowledge of epilepsy which was associated with poor self-management practices. Studies that focused on self-management reported comparisons in the domains of self-management such as safety, medication management, information management,

but none were found to comparing epilepsy knowledge and epilepsy self- management. It is therefore evident that more studies examining these two variables should be implemented in the United States especially as such data would be valuable in managing the growing epilepsy population.

DNP Role Considerations and Implications

Several DNP Essentials were addressed in this study concurrently. The most relevant to the project included;

Essentials I, Scientific underpinnings for practice.

Essential II, Organization, and systems leadership for quality improvement and systems thinking.

Essential III, Clinical scholarship and analytical methods for evidence-based practice.

Essential IV, Information systems/technology and patient care technology for the improvement and transformation of healthcare (Chism, 2015, p. 52).

In meeting essential I, the author had to demonstrate the integration of nursing science with knowledge from ethics, theory, analytical, and organizational sciences as the basis for the highest level of nursing practice. This was demonstrated in the comprehensive literature review and inter-organizational planning that was required to implement the QI study. Social cognitive theory was used to guide this study and prior scientific evidence to compare outcomes.

DNP essential II and IV were met in the use of advance system-wide clinic database to generate the desired study sample characteristics and conduct the survey using electronic media while spending minimal to no financial resources. The author used the university system and the healthcare system to implement the study while utilizing the available resources wisely.

Programs such as PsychData and SPSS needed for implementing this study were expensive and

required specialized advanced knowledge of organizational systems to access. The author was able to obtain the use of both programs at no cost through the University's research department.

Essential III formed the principal basis of the QI study. The author employed clinical scholarship in planning, proposing, and executing the study while maintaining therapeutic relationships with the patients as a provider. Professional relationships with other providers and stakeholders at the recruitment site were also carefully considered in seeking permissions to conduct the study. Analytical methods were used to critically appraise literature in preparation for the study design and implementation using best practices and evidence-based methods.

As a DNP provider, being aware of health care policies and how they impact organizations is an important framework for launching QI initiatives. With the current changes in healthcare and a shift towards value-based care, programs that demonstrate increasing value while lowering costs will be beneficial to healthcare systems nationwide (Change healthcare, 2018).

With this data, the author plans to propose and initiate the PACES program at the outpatient neurology clinic where she works. The program is paid for by the CMS and is implemented in face to face meetings that last about an hour every week for six weeks. A group of up to six patients with epilepsy can be enrolled at a time for the six-week hour-long sessions. The sessions can also be conducted via video conferencing. Epilepsy knowledge and self-management issues are among the topics addressed during these meetings. In the future, similar programs can be adapted for other chronic neurological conditions such as migraines and dementia to improve patient outcomes. An snapshot of the PACES program is included in Appendix L.

Plan for Dissemination

This study will be presented at the Graduate Research Symposium at TWU in April 2019. It will also be presented at the outpatient clinic in Dallas where participants were recruited from. There are also ongoing discussions with the Texas Epilepsy Foundation board for grants on funding a self-management program.

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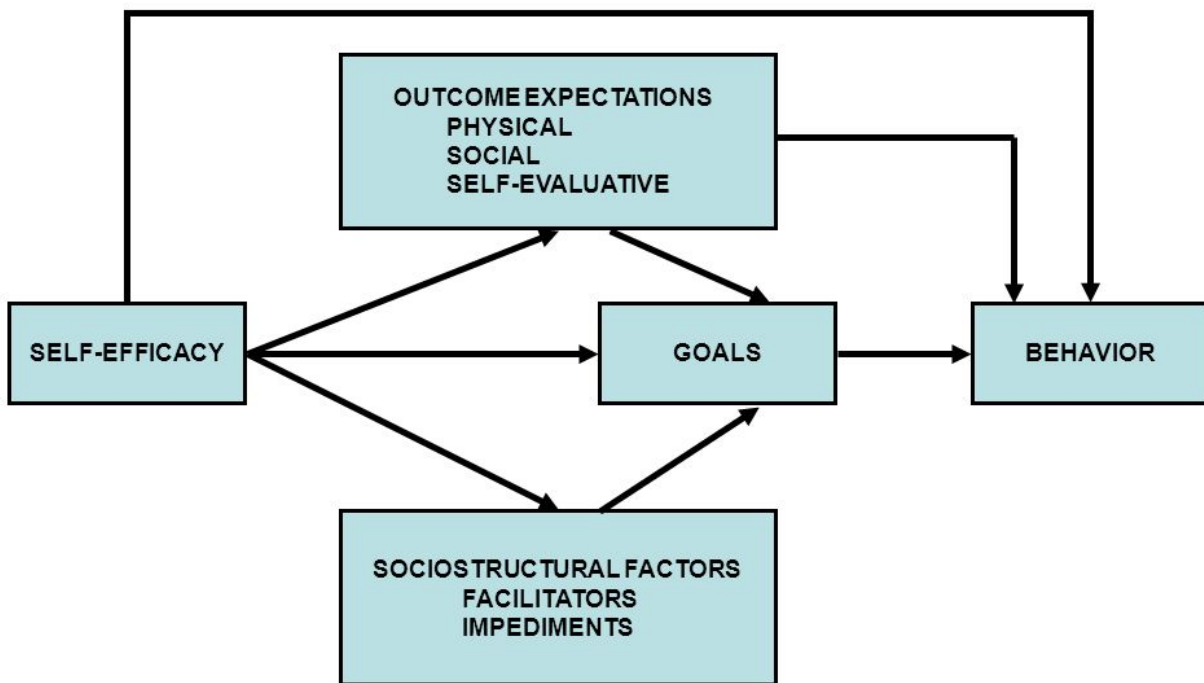
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Appendix A

Social Cognitive Theory

(Bandura, 1986, 2004)



Adapted from Bandura (2004).
Health Education & Behavior, 31, 143-164.

Copied with Permission (Appendix D)

Appendix B

SYNTHESIS OF LITERATURE AND LEVELS OF EVIDENCE

Synthesis Section	Specific Themes	Variations: Concepts	Variations: Methods and Design	Citations: Author and Year	Level of Evidence
1	Knowledge of Epilepsy	1) Knowledge needs	Report-Descriptive Cross sectional study Systematic Review	<p>Bandura, A. (2004). Health promotion by social cognitive means. <i>Health Education & Behavior, 31</i>(2), 143-164. doi:10.1177/1090198104263660</p> <p>Mameniskiene, R., Sakalauskaite-Juodeikiene, E., & Budrys, V. (2015). People with epilepsy lack knowledge about their disease. <i>Epilepsy and Behavior, 46</i>, 192-197. doi:10.1016/j.yebeh.2015.03.002</p> <p>Jones, C., Atkinson, P., Helen Cross, J., & Reilly, C. (2018). Knowledge of and attitudes towards epilepsy among teachers: A systematic review. <i>Epilepsy & Behavior, 87</i>, 59-68. doi:10.1016/j.yebeh.2018.06.044</p>	Level VII Level VI Level I

			Comparative Study	Dinta Suresh, Meena Aggarwal, Achal Srivastava, & Mamta Bhushan Singh. (2017). A comparative study to assess the knowledge of caregivers of people with epilepsy and general public regarding epilepsy and its first- aid management. <i>Asian Journal of Nursing Education and Research</i> , 7(2), 147-150. doi:10.5958/2349-2996.2017.00029.5	Level VI
			Descriptive study	Doughty, J., Baker, G., Jacoby, A., & Lavaud, V. (2003). Cross-cultural differences in levels of knowledge about Epilepsy. <i>Epilepsia</i> , 44(1), 115-123. doi:10.1046/j.1528-1157.2003.34402.x	Level VI
			Report	Price, P., Kobau, R., Buelow, J., Austin, J., & Lowenberg, K. (2015). Improving understanding, promoting social inclusion, and fostering empowerment related to epilepsy: Epilepsy foundation public awareness campaigns — 2001 through 2013. <i>Epilepsy and Behavior</i> , 44, 239-244. doi:10.1016/j.yebeh.2014.12.044	Level VII
		2)Epilepsy knowledge	Cross sectional study	Jarvie, S., Espie, C. A., & Brodie, M. J. (1993a). The development of a questionnaire to assess knowledge of epilepsy: 1—general knowledge of epilepsy. <i>Seizure: European Journal of Epilepsy</i> , 2(3), 179-185. doi:10.1016/S1059-1311(05)80125-6	Level IV

		scale development	Cross Sectional	Jarvie, S., Espie, C. A., & Brodie, M. J. (1993b). The development of a questionnaire to assess knowledge of epilepsy: 2—knowledge of own condition. <i>Seizure: European Journal of Epilepsy</i> , 2(3), 187-193. doi:10.1016/S1059-1311(05)80126-8	Level IV
			Study case controlled		
			Cross Sectional	Ross, A., Gilani, Z. A., & Naidoo, K. (2015). A review of 'medical' knowledge of epilepsy amongst isiZulu-speaking patients at a regional hospital in KwaZulu-natal : Original research. <i>African Primary Health Care and Family Medicine</i> , 7(1), 1-6.	Level VI
		3) Studies that used the scale	Study-		
			Descriptive	Vancini, R. L., Benedito-Silva, A. A., Sousa, B. S., Gomes da Silva, S., Souza-Vancini, M. I., Vancini-Campanharo, C. R., . . . de Lira, Claudio Andre Barbosa. (2012). Knowledge about epilepsy among health professionals: A cross-sectional survey in sao paulo, brazil. <i>BMJ Open</i> , 2(2), e000919. doi:10.1136/bmjopen-2012-000919	Level VI
			Cross Sectional survey	Peterson, C. L., Piccenna, L., Williams, S., Batchelor, F., Dow, B., & Shears, G. (2017). Older people and knowledge of epilepsy: GPs can help. <i>Australian Family Physician</i> , 46(3), 132-136.	Level VI

	Self- Management	Epilepsy Self- Management Instruments	Qualitative	Dilorio, C. (2010). Epilepsy self-management scale. Retrieved from http://managingepilepsywell.org/documents/instruments/Epilepsy%20Self%20Mangement-Scale%20and%20Description.pdf	Level VI
			Qualitative	Dilorio, C., Escoffery, C., McCarty, F., Yeager, K. A., Henry, T. R., Koganti, A., . . . Wexler, B. (2009). Evaluation of WebEase: An epilepsy self-management web site. <i>Health Education Research, 24</i> (2), 185-197. doi:10.1093/her/cyn012	Level VI
			Qualitative	Escoffery, C., Bamps, Y., LaFrance, W. C., Stoll, S., Shegog, R., . . . Hatfield, K. (2015). Development of the adult epilepsy self-management measurement instrument (AESMMI). <i>Epilepsy and Behavior, 50</i> , 172-183. doi:10.1016/j.yebeh.2015.07.025	Level VI
		Self- management	Concept Analysis	Garnett, A., Ploeg, J., Markle-Reid, M., & Strachan, P. H. (2018). Self-management of multiple chronic conditions by community-dwelling older adults: A concept analysis. <i>SAGE Open Nursing, 4</i> , 237796081775247. doi:10.1177/2377960817752471	Level VII

		Concept analysis	Qualitative	Fraser, R. T., Johnson, E.K., Miller, J. W., Temkin, N., Barber, J., Caylor, L., . . . Chaytor, N. (2010). Managing epilepsy well: Self-management needs assessment. <i>Epilepsy and Behavior</i> , 20(2), 291-298. doi:10.1016/j.yebeh.2010.10.010	Level VI
		Epilepsy Self-management needs and programs	Randomized Controlled Trial	Fraser, R. T., Johnson, E. K., Lashley, S., Barber, J., Chaytor, N., Miller, J. W., . . . Caylor, L. (2015). PACES in epilepsy: Results of a self-management randomized controlled trial. <i>Epilepsia</i> , 56(8), 1264-1274. doi:10.1111/epi.13052	Level II
			Randomized Controlled Trial	Leenen, L. A. M., Wijnen, B. F. M., Kessels, A. G. H., Chan, H., de Kinderen, R. J. A., Evers, S. M. A. A., . . . Majoie, M. H. J. M. (2018). Effectiveness of a multicomponent self-management intervention for adults with epilepsy (ZMILE study): A randomized controlled trial. <i>Epilepsy & Behavior</i> , 80, 259-265. doi:10.1016/j.yebeh.2018.01.019	Level II
			Randomized Controlled Trial	Magill, N., Ridsdale, L., Goldstein, L. H., McCrone, P., Morgan, M., Noble, A. J., . . . Landau, S. (2015). Self-management education for adults with poorly controlled epilepsy (SMILE (UK)): Statistical, economic and qualitative analysis plan for a randomised controlled trial. <i>Trials</i> , 16(1), 269. doi:10.1186/s13063-015-0788-9	Level II

			Qualitative	Begley, C., Shegog, R., Liu, H., Tatsuoka, C., Spruill, T. M., Friedman, D., . . . Sajatovic, M. (2018). Correlates of epilepsy self-management in MEW network participants. <i>Epilepsy & Behavior, 85</i> , 243-247. doi:10.1016/j.yebeh.2018.04.011	Level IV
			Integrative review	Edward, K. L., Cook, M., Giandinoto, J. (2015). An integrative review of the benefits of self-management interventions for adults with epilepsy. <i>Epilepsy and Behavior, 45</i> , 195-204. doi:10.1016/j.yebeh.2015.01.026	
			Systematic Review	Smith, A., McKinlay, A., Wojewodka, G., & Ridsdale, L. (2017). A systematic review and narrative synthesis of group self-management interventions for adults with epilepsy. <i>BMC Neurology, 17</i> (1), 1-10. doi:10.1186/s12883-017-0893-3	Level I
			Report	Dilorio, C., Escoffery, C., McCarty, F., Yeager, K. A., Henry, T. R., Koganti, A., . . . Wexler, B. (2009). Evaluation of WebEase: An epilepsy self-management web site. <i>Health Education Research, 24</i> (2), 185-197. doi:10.1093/her/cyn012	Level VII

	Treatment Adherence	Concept analysis	Descriptive study	Brodie, M. J. (2010). Antiepileptic drug therapy the story so far. <i>Seizure, 19</i> (10), 650-655. doi://doi.org/10.1016/j.seizure.2010.10.027	Level VI
			Systematic review	Malek, N., Heath, C. A., & Greene, J. (2017). A review of medication adherence in people with epilepsy. <i>Acta Neurologica Scandinavica, 135</i> (5), 507-515. doi:10.1111/ane.12703	Level I
			Qualitative	Náfrádi, L., Galimberti, E., Nakamoto, K., & Schulz, P. J. (2016). Intentional and unintentional medication non-adherence in hypertension: The role of health literacy, empowerment and medication beliefs. <i>Journal of Public Health Research, 5</i> (3), 762. doi:10.4081/jphr.2016.762	Level VI
			Systematic Review	Náfrádi, L., Nakamoto, K., & J Schulz, P. J. (2017). Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. <i>PLoS One, 12</i> (10), e0186458. doi:10.1371/journal.pone.0186458	Level I

			Qualitative study	Moura, L., Carneiro, T. S., Cole, A. J., Hsu, J., Vickrey, B. G., & Hoch, D. B. (2016). Association between addressing antiseizure drug side effects and patient-reported medication adherence in epilepsy. <i>Patient Preference and Adherence</i> , 10, 2197-2207. doi:10.2147/PPA.S119973	Level VI
			Meta-analysis	Yang, C., Hao, Z., Yu, D., Xu, Q., & Zhang, L. (2018). The prevalence rates of medication adherence and factors influencing adherence to antiepileptic drugs in children with epilepsy: A systematic review and meta-analysis. <i>Epilepsy Research</i> , 142, 88-99. doi:10.1016/j.eplepsyres.2018.03.018	Level I
			Report	World Health Organization. (2018). <i>Adherence to long term therapies; evidence for action</i> . (). Retrieved from http://www.who.int/chp/knowledge/publications/adherence_introduction.pdf?ua=1	Level VII

Key to Evidence Levels:

Level I Evidence

From systematic review or meta-analysis of all relevant randomized controlled trials (RCT's),
or evidence-based clinical practice guidelines based on systematic reviews of RCT's

Level II Evidence	From at least one well-designed RCT
Level III Evidence	From well-designed controlled trials without randomization
Level IV Evidence	From well-designed case-control and cohort studies
Level V Evidence	From systematic reviews of descriptive and qualitative studies
Level VI Evidence	From single descriptive or qualitative study
Level VII Evidence	From the opinion of authorities and/or reports of expert committees

Adapted from Melnyk, & Fineout-Overholt (2005). Evidence-based practice in nursing and healthcare: A guide to best practice, Rating system for the Hierarchy of Evidence, page 10.

Appendix C

Epilepsy Knowledge Profile – General Knowledge (EKP-Q)

- 1 Epilepsy is a contagious disease (F)
- 2 People with epilepsy cannot drink alcoholic beverages (F)
- 3 People with epilepsy should avoid strenuous work because this can provoke seizures (F)
- 4 An electroencephalogram (EEG) can always prove the diagnosis of epilepsy (F)
- 5 People with epilepsy are as capable as other people (T)
- 6 All people with seizures should avoid working with open machinery (F)
- 7 Every seizure destroys several nerve cells in the brain (F)
- 8 People with seizures should not swim without an accompanying person (T)
- 9 All people with epilepsy should avoid flashing or strobing lights (F)
- 10 In most cases, doctors can control epileptic seizures with medication (T)
- 11 If your seizures are controlled for some months, you can reduce the dose of anti-epileptic medication (F)
- 12 All people with epilepsy have similar symptoms (F)

13 If a patient expects a seizure, he/she should take an additional dose of anti-epileptic medication (F)

14 On a job application, a patient should always disclose his/her epilepsy condition (F)

15 People with epilepsy can take an active part in sports (T)

16 An epileptic seizure always results in loss of consciousness (F)

17 People whose seizures only occur during sleep may hold a driver's license (T)

18 Everyone can have a seizure, given the appropriate circumstances (T)

19 Blood samples can be used to measure the concentration of anti-epileptic medication in the body (T)

20 Epilepsy is a symptom of mental illness (F)

Appendix D

Albert Bandura <bandura@stanford.edu>

Fri, Sep 28, 7:13 PM (6 days ago)

to me

Permission granted, Albert Bandura.

From: CATHERINE KAMAU <ckamau@twu.edu>

Sent: Monday, September 24, 2018 4:09 AM

To: Albert Bandura

Subject: Copyright permission

Hello Prof Bandura,

My name is Catherine Kamau a Doctor of Nursing Practice student at Texas Woman's University. As part of my doctoral program requirements, I am completing a scholarly project evaluating epilepsy knowledge in patients with epilepsy and how much that knowledge influences their health behaviors. The guiding theory is the social cognitive theory, especially the knowledge of health risks and practices areas. I would like to include a copy of the structural images of the theory to my proposal paper.

Please let me know if it would be ok to include the image in my appendixes. Thank you in advance.

Catherine Kamau

CATHERINE KAMAU <ckamau@twu.edu>

Sun, Sep 30, 6:17 PM (4 days ago)

to bandura

Thank You Very Much!!!

Appendix E**Escoffery, Ngoc Cam**

3:06 PM (5 minutes ago)

to me

Hi Catherine

Good luck with your project. You can find the questionnaire attached. This site also has the data on the scale and the appropriate citation: <http://managingepilepsywell.org/documents/instruments/AESMMI%2065.pdf>

It is great to see that you are interested in measuring self-management.

Thanks,
Cam

Cam Escoffery, PhD, MPH, CHES
Associate Professor
Dept. of Behavioral Sciences and Health Education
Rollins School of Public Health, Emory University
1518 Clifton Road, NE, 5th Floor
Atlanta, GA 30322
Phone: 404-727-4701
Fax: 404-727-1369
cescoff@emory.edu

From: Catherine <ckamau@twu.edu>
Sent: Thursday, October 04, 2018 1:03 PM
To: Escoffery, Ngoc Cam <cescoff@emory.edu>
Subject: AESMMI-65 Copyright Permission

Hello Dr Escoffery

My name is Catherine Kamau a Doctor of Nursing practice student at Texas Woman's university. As part of my curriculum requirement, I am completing a Capstone project evaluating whether Epilepsy Knowledge correlates with Epilepsy self management. I am using the EKP-Q questionnaire to asses knowledge and would like permission to use the AESMMI-65 to asses self management in people with epilepsy. The project data

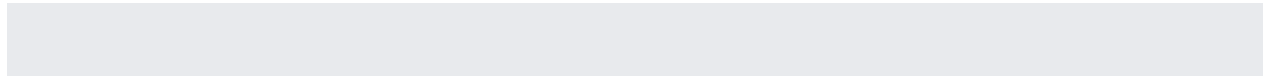
collection phase is scheduled to start in January of 2019 and hoping to close in March 2019.

Please let me know if I can use the AESMMI-65 scale for the project.

Thank you in advance.

Catherine Kamau.

Sent from [Mail](#) for Windows 10



Appendix F

Adult Epilepsy Self-Management Measurement Instrument (AESSMI-65)

The Adult Epilepsy Self-Management Scale (ESMS) is a 65-item scale that assesses frequency of use of epilepsy self-management practices. The scale was developed through multiple phases over a series of years: 1) a review of the literature on epilepsy self-management and self-management scales, 2) a review by expert panel in epilepsy management and treatment and 3) testing of the instrument with people with epilepsy.

The instrument was developed by a workgroup of researcher from the Managing Epilepsy Well (MEW) network. The instrument grouped items within 10 exploratory domains for epilepsy self-management: treatment, symptom, seizure, lifestyle, wellness, safety, information, communication, social support and stigma management. Each of the 113 items is rated on a 5-point Likert scale (i.e., none to all of the time, never to always, not at all to completely true) plus a “Not applicable” option. Total scores are found by reverse coding the 9 negatively worded items and summing responses to all 113 individual items. Total possible scores range from 113-565 with higher scores indicating more frequent use of self-management strategies.

The research team conducted testing of the 113 instrument and conduct factor analyses on the scale. Internal consistency reliability reported for the 65-item scale was 0.94 (Escoffery et al., 2015b). The alphas for the subscales ranged from 0.52 (Proactivity) to 0.90 (Health-care Communication). The 65-item scale was factor analyzed yielding 11 factors: 1) healthcare communication, 2) treatment management, 3) coping, 4) social support, 5) seizure tracking, 6) wellness, 7) seizure response, 8) safety, 9) medication adherence, 10) stress management, and 11) proactivity (Escoffery et al., 2015b). The AESMMI has acceptable internal consistency and construct validity. Participants who reported better health status or quality of life were more likely to frequently engage in epilepsy self-management behaviors ($r = .228$, $p < 0.000$ and $r = .314$, $p < 0.000$, respectively). Conversely for discriminant validity, the AESMMI was negatively associated with depression ($r = -.323$, $p = .000$), seizure severity ($r = -.109$, $p = .027$) and seizure problems ($r = -.134$, $p = .006$).

Descriptive Statistics for the Final Factors for the AESMMI-65

Domain	No. of Items	Cronbach's alpha
Healthcare Communication	14	.904
Treatment Management	11	.877
Coping	10	.868
Social Support	7	.800
Seizure Tracking	3	.868

Wellness	3	.750
Seizure Response	3	.659
Safety	4	.627
Medication Adherence	4	.563
Stress Management	3	.618
Proactivity	3	.517
Total	65	.935

References

Escoffery, C., Bamps, Y., Thompson, N., LaFrance Jr., C., Stoll, S., Shegog, R., Buelow, J., Shafer, P., McGee, R., & Hatfield, K. (2015a). Development of an Epilepsy Self-management Instrument for Adults with Epilepsy. *Epilepsy & Behavior, 50*, 172-183.

Escoffery, C., Bamps, Y., Thompson, N., LaFrance Jr., C., Stoll, S., Shegog, R., Buelow, J., Shafer, P., McGee, R., & Hatfield, K. (2015b). Factor Analyses of an Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy & Behavior, 50*, 184-189.

Adult Epilepsy Self-Management Measurement Instrument (65 items)**AESMMI-65****Anchors:**

None of the time	A few times	Some of the time	Most of the time	All the time	Not Applicable
Never	Rarely	Sometimes	Often	Always	Not Applicable
Not at all true	Rarely true	Sometimes true	Mostly true	Completely true	Not Applicable
1	2	3	4	5	MISSING DATA

Items in **bold face** are negatively phrased or need to be reverse-coded.

SCALE SCORING: Items are rated on a scale of 1 to 5 (except for those negatively phrased items, where the scale is from 5 to 1). “Not Applicable” choices should be treated as missing value. Higher scores represent more frequent use of self-management strategies.

Item	Factor	Anchors
1 I talk to my health care provider if my seizure medicine affects my emotions or the way I act (feeling depressed, anxious, irritable or edgy)	Healthcare Communication	none of time -all the time
2 I tell my healthcare provider if I have problems with my sleep.	Healthcare Communication	none of time -all the time
3 I tell my health care provider when I think I am having side-effects from my seizure medicine.	Healthcare Communication	none of time -all the time

Item	Factor	Anchors
4 I talk to my health care provider if my seizure medicine causes physical problems (for example, changes in weight, upset stomach, feeling shaky, off-balance, or tired)	Healthcare Communication	none of time -all the time
5 I talk to my health care provider if my seizure medicine affects my memory, my attention and my ability to think.	Healthcare Communication	none of time -all the time
6 I talk with my healthcare provider about the long-term effects of my epilepsy treatment.	Healthcare Communication	none of time -all the time
7 I talk to my health care provider about my emotions.	Healthcare Communication	none of time -all the time
8 I talk about how I take my seizure medicine with my health care provider.	Healthcare Communication	none of time -all the time
9 I keep track of the side-effects of my seizure medicine.	Healthcare Communication	none of time -all the time
10 I talk with my healthcare provider about my sleep habits.	Healthcare Communication	none of time -all the time
11 I set treatment goals with my healthcare provider on how to manage my epilepsy/seizures.	Healthcare Communication	none of time -all the time
12 I stay informed about what treatments I need or are available to me.	Healthcare Communication	none of time -all the time
13 I talk to my health care team if I am too tired or sleepy during the day.	Healthcare Communication	none of time -all the time
14 I call my health care provider if I am having more or different seizures than usual.	Healthcare Communication	none of time -all the time
15 I put off having my seizure medicine refilled.	Treatment	none of time -all the time
16 When my seizure medicine is running out, I spread out the time between doses.	Treatment	none of time -all the time
17 I plan ahead so that I do not run out of my seizure medicine.	Treatment	none of time -all the time
18 When my seizure medicine is running out, I take less medicine each day.	Treatment	none of time -all the time

Item	Factor	Anchors
19 I skip doses of seizure medicine without checking with my healthcare provider.	Treatment	none of time -all the time
20 Before my seizure medicine runs out, I get it refilled.	Treatment	none of time -all the time
21 When my seizure medicine is running out, I stop taking it.	Treatment	none of time -all the time
22 I forget to take doses of my seizure medicine.	Treatment	none of time -all the time
23 I have blood tests or other tests done when ordered by my healthcare provider.	Treatment	none of time -all the time
24 I take my seizure medicine as prescribed even on holidays, birthdays, vacations and other special occasions.	Treatment	none of time -all the time
25 I keep healthcare provider or clinic appointments.	Coping	none of time -all the time
26 I do things that I enjoy with my family and friends despite my epilepsy/seizures	Coping	none of time -all the time
27 I continue my hobbies or recreation despite my epilepsy/seizures.	Coping	none of time -all the time
28 I do things that I enjoy to help manage stress.	Coping	none of time -all the time
29 I have ways to change my negative thinking.	Coping	none of time -all the time
30 I have healthy ways to solve problems related to my epilepsy/seizures	Coping	none of time -all the time
31 I set long-term goals for my life.	Coping	none of time -all the time
32 I have healthy ways to cope when I am feeling sad or down.	Coping	none of time -all the time
33 I have ways of dealing with physical pain or discomfort so that it does not interfere with the things that I want to do.	Coping	none of time -all the time
34 I have ways to make sure that my fatigue does not interfere with the things that I want to do.	Coping	none of time -all the time

Item	Factor	Anchors
35 I have ways to manage my worries or fear about having another seizure.	Coping	none of time -all the time
36 I get family and friends to help me with the things I need (such as household chores, shopping, cooking, or transportation).	Social Support	none of time -all the time
37 I seek emotional support from family and friends.	Social Support	none of time -all the time
38 I get the help I need with problems at home, work, school, or other community settings.	Social Support	none of time -all the time
39 I have ways to get help if I have a seizure.	Social Support	none of time -all the time
40 I talk with someone about my epilepsy/seizures when I need to.	Social Support	none of time -all the time
41 I talk to my family or my friends about their worries about my epilepsy/seizures.	Social Support	none of time -all the time
42 I tell people who need to know that I have seizures	Social Support	none of time -all the time
43 I keep track of when my seizures occur.	Seizure Tracking	none of time -all the time
44 I keep track of how often I have seizures.	Seizure Tracking	none of time -all the time
45 I keep a record of the types of seizures I have.	Seizure Tracking	none of time -all the time
46 I do things to maintain a healthy weight.	Wellness	none of time -all the time
47 I eat a healthy diet almost every day.	Wellness	never-always
48 I exercise at least half an hour most days of the week.	Wellness	Never-always
49 I teach my family and friends what to do during a seizure.	Seizure Response	none of time -all the time
50 I teach others not to put something in my mouth when I have a seizure.	Seizure Response	none of time -all the time

Item	Factor	Anchors
51 I have seizure drills with my family and friends so that they know what to do when I have a seizure.	Seizure Response	not at all true-completely true
52 I use safety precautions when I cook.	Safety	none of time -all the time
53 I use safety precautions if I take a shower.	Safety	none of time -all the time
54 I climb on high stools, chairs, or ladders when I need to reach something.	Safety	none of time -all the time
55 I take steps to stay safe when I have a seizure.	Safety	none of time -all the time
56 I take my seizure medicine the same way every day.	Medication Adherence	none of time -all the time
57 I take my seizure medicine at about the same time each day.	Medication Adherence	none of time -all the time
58 I take my seizure medicine the way my healthcare provider prescribes it.	Medication Adherence	none of time -all the time
59 I plan my seizure medicine schedule around things that I do every day.	Medication Adherence	none of time -all the time
60 I do things such as relaxation or breathing exercises to keep myself from having seizures or to stop them.	Stress Management	none of time -all the time
61 I use/I have used non-medical techniques in addition to my treatment to keep myself from having seizures.	Stress Management	none of time -all the time
62 I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress.	Stress Management	none of time -all the time
63 I check with my doctor, nurse or pharmacist before taking other medicines.	Proactivity	none of time -all the time
64 I bring an up-to-date list of all my medicine to healthcare provider's appointments.	Proactivity	none of time -all the time
65 I avoid situations or things that might cause seizures.	Proactivity	none of time -all the time

Appendix G

Study ID Number: _____

Age: _____

Gender: _____

Number of seizures per month: _____

Work Status: Unemployed _____ Employed Full-Time _____ Employed Part-Time
_____ Retired _____

Living Situation: Alone _____ With Another Person _____ In a Facility _____

Marital Status : _____

Level of education (number of years of school completed): _____

Length of time since epilepsy diagnosis: _____

Appendix H

Receipt Notification for Protocol # 20293

IRB

Oct 9, 2018, 11:24 AM (1 day ago)

to me, Sheila

Ms. Kamau,

Your application has been received for the study "Epilepsy Knowledge Profile and Self Management; A quality improvement study " and has been assigned a protocol number (referenced above). Because it has been determined that this study falls under the category of a class project, this study does not need IRB Review. If you have any questions regarding this determination, please feel free to contact the IRB office at 940-898-3378 or email irb@twu.edu. You may also contact the IRB chair at swang@twu.edu.

Thank you,

Sandy N. Owens
Project Coordinator

Texas Woman's University
Research & Sponsored Programs /
Institutional Review Board
irb@twu.edu | sowens6@twu.edu
Phone: 940 898-3378

Appendix I

9/25/18

To whom it may concern,

This is to document that Neurology Consultants of Dallas PA has given permission to Catherine Kamau APRN, a DNP student at Texas Woman's university, to conduct her epilepsy knowledge evaluation project at our Clinic.

Thank you

A handwritten signature in black ink, appearing to read 'Kevin Wilson', with a long horizontal stroke extending to the right.

Kevin Wilson
CEO
Neurology Consultants of Dallas

Appendix J

Epilepsy Questionnaire

X

CATHERINE KAMAU <ckamau@twu.edu>

**Thu, Jan 24,
3:03 PM**

Dear Participant,

I am conducting a survey to asses Epilepsy Knowledge and Self-Management in patients with epilepsy. This will assist me in implementing educational programs at the clinic in the future and is part of my Doctoral Program requirements.

To participate, please click on the following link:

<https://www.psychdata.com/s.asp?SID=184756>

My survey is titled: "Epilepsy Knowledge and Self-Management Questionnaire"

Thank you,

Catherine Kamau RN, MS, ANP-C

ckamau@twu.edu

Appendix K

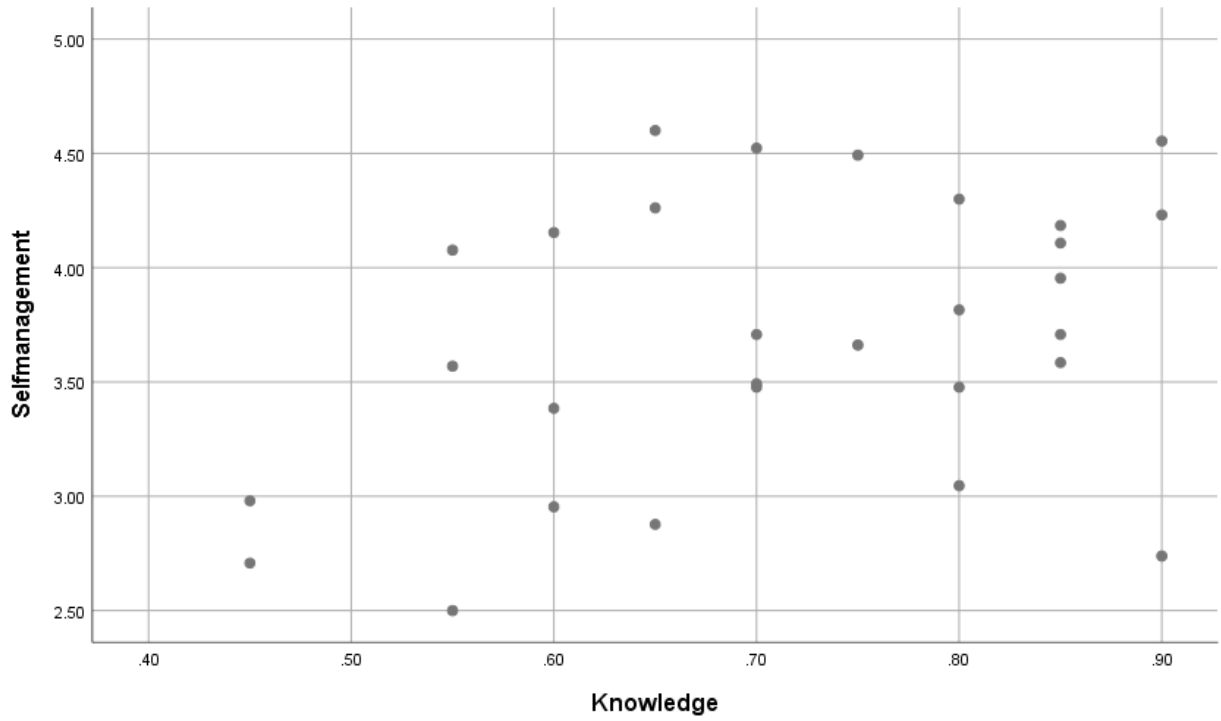


Figure 1. Graph showing Self- management scores vs Knowledge scores

Appendix L

PACES Program Snapshot

KEY COMPONENTS

- **Education** about seizure types and available treatments, the influence of epilepsy on mood, stress, and cognition, and strategies for healthy lifestyle and active community engagement.
- **Training and practice** using specific strategies to cope with stress and the blues.
- **Personalized goal-setting and support** to help you articulate and pursue life changes that are important to you.
- **Qualified facilitator tandem** to include a trained epilepsy mental health professional and a trained peer with epilepsy.
- **A group program in-person or by phone**, depending on what works best for the participant.

Session Topics:

1. Epilepsy and Medical Issues
2. Dealing with Stress and The Blues (I)
3. Dealing with Stress and The Blues (II)
4. Compensating for Cognitive Challenges
5. Getting the Most out of Community Living
6. Managing My Epilepsy Care
7. Effective Communication About My Epilepsy
8. My Health and Wellbeing

Program Description

The goal of PACES is to increase the medical, psychosocial, and community adjustment of adults with active seizure conditions.

Participants develop coping and goal-setting strategies that improve overall and discrete aspects of quality of life, epilepsy self-management and efficacy, and anxiety and depression.

PACES is an eight-session epilepsy self-management program developed with direct input from adults with epilepsy at the University of Washington Epilepsy Center / Health Promotion

Research Center and subject to randomized control evaluation with funding from the Centers for Disease Control and Prevention (CDC).

FORMAT

8 group sessions (in person or by phone).

PARTICIPANTS

Adults with epilepsy.

FACILITATORS

Mental Health Professional and a Peer Facilitator with epilepsy.

RESOURCE REQUIREMENTS

- Telephone conference line and toll-free number; a private conference room if offering the group in person.
- Two facilitator manuals, participant manuals, and stress reduction CDs.
- Staff or volunteer time outside of group sessions to (a) screen potential candidates for program eligibility; (b) send weekly follow-up information to participants in relationship to lifestyle goals; (c) make weekly reminder calls in advance of session meetings; and (d) follow up with participants after the program has ended.
- If conducting the group in person, consider light refreshments.

COSTS

The cost of PACES delivery will vary based upon staffing and the number of participants in a group.

Utilizing a mental health professional (\$75-\$175 per hour) and a trained peer facilitator (\$50 per hour), the 8-week program with six participants, includes screening, participant manuals, pre-session review, and follow-up. Using these figures, the cost of running a group of six would be \$2,900.

At present, training is sponsored by the CDC at no cost.
