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NURSING PERCEPTION OF PSYCHOGENIC NONEPILEPTIC SPELLS:
IMPROVING PATIENT OUTCOMES

Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Nursing Practice

by

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2016

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Executive Summary

Patients with psychogenic nonepileptic spells (PNES) have generally poor outcomes and many fail to engage in evidence-based treatments (Thompson et al., 2013). Negative healthcare provider perceptions have been implicated as a barrier to patient engagement in treatment recommendations for PNES (Whitehead, Kandler, & Reuber, 2013; Worsely et al., 2011). Illness perception of these patients has been evaluated from the perspective of physicians in multiple settings but perceptions by nurses are not well studied despite the close interactions that nurses have with these patients.

This project used Pender's health promotion model to collect information about the nursing experience with patients with PNES at one facility. Using a quantitative translational design, 51 inpatient neurology nurses at Grant Medical Center in Columbus, Ohio were surveyed using the Illness Perception Questionnaire-Revised (IPQ-R) and a 21-item questionnaire previously used to assess physician knowledge and perceptions of PNES. After establishing existing nursing perceptions and knowledge, a brief education intervention was implemented. The questionnaires were administered pre- and post-intervention to evaluate if a brief education intervention can influence nursing knowledge and perceptions regarding patients with PNES.

This project revealed that the neurology nurses at GMC held many misconceptions and poor perceptions about PNES and nurses had a low level of self-perceived competency in caring for patients with PNES. After the intervention, nurses demonstrated improved knowledge, perceptions and self-perceived competency about the condition. This project indicates that a brief education intervention can influence nursing knowledge, perceptions and self-perceived competency. Further research is indicated to determine if improving nursing perceptions influences nursing behaviors that can promote patient engagement in treatment recommendations and thus improve patient outcomes.

I. Introduction

Clinical Problem

Psychogenic nonepileptic spells (PNES) are involuntary paroxysmal behavior events that may resemble epileptic seizures. These spells are part of a subset of conversion disorders caused by a psychological conflict rather than a neurological cause and treatments used for epileptic seizures are not effective for treating PNES (Bodde et al., 2009; LaFrance et al., 2014; Dickerson & Looper, 2012). Despite evidence for improved outcomes with psychotherapy nearly half of patients fail to engage in evidence based treatment recommendations (Mayor et al., 2013; Thompson et al., 2013; Chen et al., 2014; LaFrance et al., 2014).

Clinical Needs Assessment

Negative health caregiver perception is associated with increased healthcare utilization and adverse treatment effects (Whitehead, Kandler, & Reuber, 2013). Negative illness perceptions of patients with PNES have been identified from the perspective of physicians and other healthcare professionals in various healthcare settings but nursing perceptions have not been well studied (Whitehead et al., 2013; Sahaya, Dholkia, Lardizabal and Sahota, 2012). Negative nursing perceptions have been linked to negative patient outcomes in other patient populations such as patients being treated for obesity and substance abuse (Brown, 2006; Chang & Yang, 2013; Malterud & Ulriksen, 2011; Moyers, Bugle, & Jackson, 2005). According to Sahaya et al. (2012), the opinion of nurses regarding PNES is crucial due to the close interactions that nurses have with admitted patients.

Grant Medical Center (GMC) is a 381-bed urban hospital in Columbus, Ohio (American Hospital Directory, 2015). The hospital is part of the OhioHealth system, which includes a Level 4 Comprehensive Epilepsy Center in Columbus, Ohio (National Association of Epilepsy Centers, 2007). The medical center reports that between the years of 2013 and

Table 1. Incidence of Patients with Nonepileptic Spells at Grant Medical Center as Captured by IDC9 Code			
Year	2013	2014	2015
Inpatient	39	38	33
Observation	33	51	56
Outpatient	132	206	227
Total	204	295	316

2015 an average of 272 patients presented annually with the primary complaint of PNES. These data do not include the patients

with suspected, not confirmed nonepileptic spells or patients that presented with another primary diagnosis (K. Hopkins, personal communication, August 5, 2015; Table 1).

The hospital has two units equipped with continuous electroencephalography (EEG) for the evaluation of seizures or suspected nonepileptic spells for inpatients. Nurses on these units have close interaction with these patients, providing 24-hour care during the time that patients are being evaluated and diagnosed. Currently, there is no formal epilepsy or PNES training for nursing staff. The close interactions that nurses have with patients provide opportunity for therapeutic communication and health promotion. Studies indicate negative illness perceptions by nurses can result in poor patient outcomes (Brown, 2006; Chang & Yang, 2013; Malterud & Ulriksen, 2011; Moyers et al., 2005). The nursing perceptions, attitudes and knowledge in of nurses at GMC have not previously been evaluated.

II. Problem Statement

Negative healthcare provider attitudes and perceptions of patients with psychogenetic nonepileptic spells are associated with poor patient outcomes. The illness perception of patients with psychogenetic nonepileptic spells by inpatient nurses at GMC that have close interactions with these patients is not known.

III. Background and Significance

Psychogenic nonepileptic spells are noted to occur around the world and the disorder is as disabling as epilepsy (LaFrance et al., 2014). The diagnosis is associated with high unemployment rates, significant injuries, suicide attempts, recurrent hospitalizations,

and low healthcare quality of life scores (Thompson et al., 2013; Karakis et al., 2014; Bodde et al., 2009). The high rate of treatment failure leads to poor patient outcomes and substantial healthcare costs.

The costs associated with PNES prior to establishing a diagnosis was estimated at \$100,000 per patient in 1995 (Bodde et al., 2009). The estimated lifetime cost of treating a patient with PNES ranges from \$110 to 920 million dollars (Karakis et al., 2014). Many patients with PNES tend to frequently seek medical attention. One-third of PNES patients have had at least one prolonged spell that was misdiagnosed as status epileptics, triggering costly, dangerous, and unnecessary treatments. As many as 91% of patients with PNES have been prescribed antiepileptic medications at some point, which are shown to be ineffective and associated with adverse reactions (Bodde et al., 2009). Bodde et al., report an 84% reduction in seizure related treatment costs once a diagnosis of PNES is established and patients are prescribed appropriate treatments (2009).

The incidence and prevalence of PNES is thought to be underestimated due to high number of unreported and misdiagnosed cases. The current estimated prevalence of PNES in the general population is from 2-33 per 100,000 with a much higher prevalence documented when estimating prevalence based on neurology referrals (Bodde et al., 2009; Duncan, Razvi & Mulhern, 2011). Epilepsy centers report that 10-22% of patients referred are found to have PNES (Asadi-Pooya & Emami, 2013; Shneker & Elliott, 2008). The diagnosis is associated with a high rate of disability and poor outcomes. Sixty percent of PNES patients diagnosed continue to have spells five years after diagnosis (Thompson et al., 2013).

Patient outcomes improve with treatment plans that include psychogenic therapy such as cognitive behavioral therapy (LaFrance et al., 2009; LaFrance et al., 2014). The ultimate goal of PNES treatment is elimination of spells but treatment success is measured

by decreased frequency of spells and or intensity of spells and improved quality of life (Karakis et al., 2014; LaFrance et al., 2009). In clinical trials, patients have shown reduction in symptoms and improved Quality of Life (QOL) scores with cognitive behavioral therapy (LaFrance, 2009; LaFrance 2014; Chen et al., 2014).

Despite the evidence for improved outcomes with cognitive behavioral therapy (CBT), many patients fail to embrace the diagnosis and fewer than half of patients diagnosed with PNES engage in treatment recommendations for psychotherapy (LaFrance et al., 2009; LaFrance et al., 2014; Mayor et al., 2013). Studies by Thompson, Osorio and Hunter (2009), Thompson et al. (2013), Chen et al. (2014), and Mayor et al. (2013) found that measures such as patient engagement in treatment recommendations, QOL scores and reduction of symptoms improve when interventions were implemented to improve communication to the patient regarding the diagnosis. These studies highlight the importance of effective communication about the diagnosis for improved patient outcomes. A lack of knowledge about the diagnosis or negative attitudes towards the diagnosis can inhibit provider communication with the patient.

Misconceptions and negative attitudes about PNES by physicians and other healthcare providers have been indicated as a barrier to effective delivery of the diagnosis, poor patient engagement and poor patient outcomes (Sahaya et al., 2012; Whitehead et al., 2013; Shneker & Elliot, 2008). These studies have indicated that healthcare providers have a poor understanding of PNES and many misconceptions about the disorder are frequently identified (Shneker & Elliot, 2008; Worsely, Whitehead, Kandler & Reuber, 2011; Sahaya et al., 2012). One study found that 72% physicians surveyed felt that their patients did not accept the diagnosis of PNES (Shneker & Elliott, 2008). The low rate of patient acceptance correlated with the treating physicians' misconceptions regarding PNES that was identified during that study. Simultaneously, 38% of physicians indicated that they felt that patients

with PNES were “fakers” and only 37% of respondents indicated that EEG is indicated for diagnosis.

In a study of 115 healthcare providers, including 39 inpatient neurology nurses, 48% of nurses surveyed felt that PNES symptoms occurred voluntarily and that patients were “fakers”. Despite the many misconceptions demonstrated by the survey, nurses overall demonstrated a high level in self-confidence in their ability to manage patients with PNES. Nurses also indicated that they felt it was appropriate to use confusing and pejorative terms such as “hysterical seizures,” “pseudoseizures,” and “fake seizures” (Sahaya et al., 2012).

Interventions to improve the attitudes and knowledge of PNES in nurses caring for these patients can positively influence patient outcomes. Patient engagement in treatment recommendations and patient outcomes are noted to improve when measures are made to enhance therapeutic communication surrounding the diagnosis (Thompson et al., 2009, Thompson et al., 2013; Chen et al., 2014; & Mayor et al., 2013). This project sought to identify the knowledge and perception of inpatient neurology nurses at GMC and to determine if an education intervention can improve nursing knowledge and perceptions to improve patient outcomes and medical center performance.

IV. Project Implementation and Measures

Methodological Approach

This project used a quantitative translational design with the use of questionnaires to collect information about the nursing experience with patients with PNES. Prior to implementation, meetings were held with the unit managers and directors to engage nursing leadership in the project. During this time nursing leadership committed to provide staff nursing time to participate in the study. Project goals, objectives, and implementation planning were also discussed. Time was scheduled for study implementation during unit staff meetings during to administer the questionnaires and to implement the education

intervention. During the study period staff were provided time to participate during work hours at scheduled staff meetings. Participation was optional. A sheet with standardized instructions and a signature line was used ensure informed consent (Appendix A).

Participant identifiers in this project were not associated with their responses.

Project Objectives

Nurses were surveyed to describe the perceptions and attitudes of inpatient neurology specialty nurses regarding patients with psychogenic nonepileptic spells and to test the hypothesis that a brief education intervention can improve nursing perceptions and knowledge of patients with PNES. The education intervention was designed to address common misconceptions, improve nursing perception, and to encourage health-promoting behaviors such as therapeutic nursing communication for patients with PNES. Outcomes were measured by evaluating scores on the pre- and post-intervention Illness Perception Questionnaire-Revised and on the Knowledge and Perception Questionnaire (adapted from Shneker & Elliot, 2008).

Theoretical framework

Pender's health promotion model was selected as the theoretical framework for this project. The health promotion model is a middle range nursing theory influenced from Bandura's social learning theory and Fishbein's theory of reasoned action. Pender's model demonstrates a broad view of nursing and healthcare that defines the goal of nursing care as optimal health (Butts & Rich, 2014). There are three major components of the health promotion model: person, environment and health. According to the model, the role of the nurse in health promotion focuses on raising consciousness to factors that are amendable to change to promote health behaviors within the concept of environment. The nurse can encourage health-promoting behaviors, promote self-efficacy, and control the environment to support change (Butts & Rich, 2014; Pender, Murdaugh & Parsons, 2011). Through the

components of Pender's model, nurses can enhance patient engagement in health promoting behaviors through the concept of environment through therapeutic interactions (Pender, Murdaugh & Parsons, 2011).

Pender primarily focused on influencing the behavior of patients but the propositions of the model can also be applied to health promotion behaviors of healthcare providers. The health promotion model has been used to explain the relationship between the perceptions of health professionals and the healthcare they provide (Moyer, Bugle & Jackson, 2005). The health promotion model has been used to as a framework to determine nursing perceptions and knowledge of school nurses related to controlling childhood obesity (Moyer, 2005). Esposito and Fitzpatrick used Pender's model as the framework to evaluate the relationships between nurses' beliefs regarding the benefits of exercise, their exercise behaviors and their recommendations of exercise for health promotion for clients (2011).

According to the health promotion model, for a nurse to foster health-promoting behaviors for patients with PNES the nurse must be knowledgeable about PNES and feel competent in his or her ability to assists patients in achieving their healthcare goals. A nurse's perceived barriers can constrain commitment to actions that influence changes, thus preventing behaviors that promote client health behaviors. If the nurse has perceived competence or self-efficacy to perform behaviors it increases the nurse's commitment to actions and actual performance of the behaviors (Moyer, Bugle & Jackson, 2005; Pender et al., 2011). This project used the health promotion model to influence nursing knowledge and attitudes to promote improved patient outcomes.

Conceptual framework

The logic model was chosen as the evaluation model for this project. This model uses a detailed plan that establishes evaluation of measures of performance throughout the

course of the program. If endpoints, or outcomes, are not being attained, the program can be modified (Hickey, & Brosnan, 2012). The logic model describes inputs, which describe the structural components of the project, such as the protocols, the environment, financial resources, and available personnel (Hickey, & Brosnan, 2012). Inputs for this project include the number of staff nurses, time available for nursing education, and administration approval for program. The activities for this project, or the processes that take place during the project, were the pre-intervention survey, the education intervention and the post-intervention survey (Hickey, & Brosnan, 2012).

There are generally three types of endpoints in logic model, outputs, outcomes and impacts. Output is the immediate consequence of the activities, such as the number of nurses that complete PNES perception questionnaires. Outcomes are used to describe program performance. This will include describing the nursing perception of PNES and establishing if a brief education intervention improved nursing perception of patients with PNES. The final endpoint described by logic model is impacts. This the term used to represent the long-term change. For this project the impact is improved patient outcomes for patients diagnosed with PNES. Although this is the long-term goal of the project, the impact is not measured for this project.

Sample

Registered nurses that provide care for patients on the inpatient neurology units at Grant Medical Center, in Columbus, Ohio were recruited for this project using voluntary, convenience sampling. There are two inpatient neurology units at the selected facility that are equipped with long term monitored video EEG capability. These two units (Medical Intermediate Unit/Neuro-Medical Intermediate Unit and the Neuro-Medical Stroke Unit) are the designated areas for PNES evaluation. There are 77 registered nurse positions between the 2 units. During the time of the study period 75 of those positions were filled.

All nurses employed on the selected the units during the project time period were given the opportunity to participate. Exclusion criteria included nurses that were absent from staff meetings for any reason during the study period.

Protection of Human Subjects

To assume risk to human participants were minimized this project was evaluated and approved by both the Otterbein University and OhioHealth Institutional Review Boards (IRB) (Appendix F). To ensure informed consent a sheet with standardized instructions with a signature line was used. Participation was voluntary and confidential.

Instruments and Tools

A series of 3 questionnaires were administered to participants both pre- and post-intervention (see Appendix B). The first questionnaire is the Illness Perception Questionnaire-Revised (IPQ-R). The IPQ-R is a standardized, validated tool that was designed to be adapted to evaluate illness perceptions of specific conditions. The IPQ-R has previously been adapted for the use of measuring illness perception of patients or caregivers of patients with functional weakness, diabetes, and epilepsy (Worsely et al., 2011; Whitehead et al., 2013). An adapted version of the tool has been used to measure the illness perception of patients and caregivers of patients with PNES in previous studies (Moss-Morris, et al., 2002; Worsely et al., 2011).

The IPQ-R is a 38-item questionnaire that asks respondents to rate each item on a 5-point Likert-type scale. Items collect data in eight separate subscales. The IPQ-R has been shown to have good levels of both internal consistency and test-retest reliability (Moss-Morris et al., 2002). The first subscale, illness identity was not used in this project, which is consistent with the tools use in previous studies when adapted for the use of evaluating caregiver perceptions (Worsely et al., 2011).

A second questionnaire with items specific to evaluating healthcare provider perceptions, knowledge and self-perceived competency of caring for patients with PNES was also administered. This Knowledge and Perception Questionnaire was adapted from the Pseudoseizure Questionnaire used in the Shenker and Elliott study (2008). The Pseudoseizure Questionnaire was drafted to assess attitude and beliefs, physician referral patterns, comfort level in diagnosing PNES, and beliefs about diagnostic techniques and treatments (Shneker & Elliot, 2008). For the Knowledge, Perception and Self Perceived Competency Questionnaire, minor word changes were made to questions numbered 2, 11 and 15 to adapt the tool to evaluate nurses' perceptions, attitudes and self-perceived competency. Participants were also asked to complete a demographics questionnaire to evaluate variables such nursing experience, education and gender.

Pre-intervention questionnaires were administered during scheduled staff meetings between January 18, 2016, and January 25, 2016. The education intervention was implemented during scheduled staff meetings between February 22, 2016, and February 25, 2016. The same three questionnaires were administered immediately following the education intervention presentation. All nurses that attended the staff meetings were invited to participate in the education and post education surveys. Participants were asked to indicate on their instruments if they had participated in the pre-intervention surveys. Participants that did not complete the pre-intervention survey were not included in the analysis.

Surveys were collected using paper and pencil questionnaires. The survey coversheets were detached from the questionnaires to maintain participant confidentiality and participants submitted their surveys and survey coversheets separately into a box at the end of the staff meetings. The process of collecting, scoring and entering survey information into the database began following each staff meeting.

The education intervention included a 30-minute live presentation to explain the diagnosis, discuss common misconceptions, and describe evidence-based nursing interventions for PNES and guidelines for patient communication regarding the diagnosis and inpatient nursing interventions (Appendix C). Content of the education intervention was reviewed by two epileptologists from the OhioHealth Corporation to assure content accuracy.

Demographic data and consent forms were collected separately from questionnaires. Data was entered into an electronic spreadsheet (Microsoft Excel) on a password-protected computer after surveys were completed. After data were entered the paper and pencil surveys were shredded to prevent any potential of identifying handwriting. Throughout the course of the project, questionnaires and signed coversheets were stored in a locked file cabinet. The survey cover letters will be shredded after the project is completed.

Table 2. Project Timeline	
Date/Start Date	Objective
02/12/2015	Meeting with nursing leadership
04/14/2015	Meeting with clinical advisor
04/22/2015	Meeting with preceptor/clinical expert
06/05/2015	Begin clinical immersion hours
06/05/2015	Project planning
08/30/2015	IRB applications submitted
11/25/2015	Otterbein IRB approval
01/05/2016	OhioHealth IRB approval
01/07/2016	Survey packets created
01/19/2016- 01/25/2016	Implementation of pre-intervention questionnaires
02/22/16- 02/25/2016	Implementation of education intervention with post intervention questionnaires
01/25/2016- 02/26/2016	Survey scoring and data entry
02/29/2016- 03/11/2016	Data analysis and interpretation Meet with content experts and advisors
07/2016- 03/14/2016	Conclusion and review, complete report

Completed results are available upon request to study participants. Follow up information regarding completion of the project was available at staff meetings through the project leader and nursing unit managers.

Timeline

Project planning began in February, 2015. At this time the meetings were held with nursing leaders at the selected facility where the project would take place in order to identify the target population, identify resources and to gauge leadership support for the project. In the following months, the project leader met with academic advisors from Otterbein University as well as clinical experts and project advisors from OhioHealth. Once the project was planned, the Institutional Review Board (IRB) application process was started. By August, 2015, applications had been submitted for approval for both Otterbein University and the OhioHealth IRB (Table 2).

Project implementation was planned pending IRB approval. IRB approval had first been obtained from the Otterbein University IRB in August 2015 and the proposed implementation timeframe was pending OhioHealth IRB approval. Final IRB approval was obtained on January 5, 2016. After IRB approval, survey packets were made with the selected questionnaires and survey cover sheets. Meetings were scheduled with unit nursing managers to plan implementation of the project. On January 12, 2016, and January 13, 2016, meetings were held with the appropriate unit managers to schedule to pre-intervention survey dates as well as the intervention and post-intervention survey dates at the subsequent monthly staff meetings in February.

The first nursing perception questionnaires were administered January 19, 2016, thru January 25, 2016. During the subsequent monthly staff meetings from February 22, 2016, through February 25, 2016, the education intervention was implemented with administration of the post intervention-questionnaires immediately following the education

presentation. Data analysis and interpretation were completed from February 25, 2016 through March 11, 2016. Final analysis was complete and the final project report draft was complete on March 14, 2014 (Table 2).

Budget

Supplies needed for this project
included paper copies of all questionnaires.
Licenses for software used for this project,

Table 3. Budget		
Item	Projected	Actual
Survey Packets	\$175.00	\$123.84
Travel Costs	\$100.00	\$100.00
Nursing Salaries	\$5000.00	\$2430.00
Project Leader Hours	300	319
Total	\$5275	\$2653.84

including Microsoft Excel, PowerPoint, and Minitab Express for Mac had already been obtained. The completed survey packet included seven pages. This included two copies of the survey cover letter, one for the participants to keep for reference and one to maintain as evidence of informed consent. The packets also included the IPQ-R, the Knowledge and Perception Questionnaire, and the demographics questionnaire. Enough copies were made for all 60 potential participants to complete the survey packet twice. The cost was initially estimated to include all potential registered nurse positions with a potential of 77 potential participants with a budget of \$175. The final cost of preparing survey packets was \$123.84 (Table 3). Project leader's travel time to and from the project location was estimated at \$100 for gas and travel expenses. This was the budgeted amount as well. The project leader funded the costs of survey packets, software, and travel.

The cost of nursing salaries for nonproductive time to participate in the project was estimated at \$5000. This estimate was determined based off the initial request to include up to 77 participants. The number of participants, and the level of experience (directly influencing nursing salaries) were lower than anticipated. The actual cost was estimated at \$2065.50. This was calculated by multiplying the average nursing salary on the two units (\$27) by the estimated participation time (90 minutes) times the number of actual participants (51). The nursing units at the facility paid the cost of nursing salaries.

The project leader's time was donated to apply for IRB approvals, to develop the education intervention, to make survey packets, to attend all staff meetings for both neurology-nursing units for the months of January and February, and to analyze and interpret data. The estimated amount of time needed for this was 300 hours. Upon completion of the project, the project leader donated 319 hours for the project preparation, implementation, and data analysis and data interpretation (Table 3).

V. Analysis and Outcome Evaluation

Data Analysis

Descriptive and inferential statistics were used to evaluate the results of the IPQ-R. Scores from the IPQ-R were calculated and entered into a spreadsheet. Excel and Minitab Express were used to calculate medians, means, and interquartile ranges of the IPQ-R subscores to make comparisons between the pre- and post-intervention scores. Data were interpreted based on the authors' definition of scores for each subscale (Moss-Morris et al., 2002) (Table 5). Inferential statistics were used to measure differences of the pre- and post-scores on the IPQ-R using 2-sample t-tests.

Qualitative data from the opened ended question on the IPQ-R was transcribed into an Excel spreadsheet. Common phrases were coded and a content analysis was made to detect themes. Common themes were ranked by importance as indicated by participants on the questionnaire and by frequency.

Data from the Knowledge and Perception Questionnaire were entered into a spreadsheet and exported into Minitab Express. Pearson's Chi-squared tests compared pre- and post-intervention questionnaire data. Continuous data were compared by analyzing 2-sample t-tests. Demographic surveys were also entered in Microsoft Excel. Descriptive statistics were calculated for demographic data and categorical results. All data was calculated at a 95% confidence interval with p-values of <0.05 considered significant.

Results

Demographics.

There were fifty-one nurses present and consented to participate in the pre-intervention survey. Thirty-five participants completed both the pre and post

Table 4. Demographics Data					
		Pre-Survey n=51		Post-Survey n=35	
Gender	Male	8	15.7%	7	20.0%
	Female	43	84.3%	28	80.0%
Years in practice	0-5	40	78.4%	28	80.0%
	6-10	2	3.9%	2	5.7%
	>10	9	17.6%	5	14.3%
Years in practice with neurology patients	0-5	42	82.4%	30	85.7%
	6-10	4	7.8%	3	8.6%
	>10	5	9.8%	2	5.7%
Education level	ADN	14	27.5%	11	31.4%
	BSN	34	66.7%	21	60.0%
	MSN	3	5.9%	3	8.6%
Have you had special training in epilepsy or PNES in the past 5 years	Yes	1	2.0%	0	0.0%
	No	50	98.0%	35	100%
Do you have a neurology specialty certification	Yes	0	0.0%	0	0.0%
	No	51	100%	35	100%

intervention survey. The majority of nurses surveyed (84.3%) were female. The nurses primarily have a low level of nursing experience with 78.4% with less than 5 years of nursing experience and 82.4% with 5 years or less experience with neurology patients. The education level was distributed with 34 (66.7%) bachelors prepared, 14 (27.5%) associates prepared and 3 (5.9%) nurses have a master's degree in nursing. None of the nurses surveyed have a specialty certification in neurology and only one of the participants indicated prior training in epilepsy or PNES in the past 5 years (Table 4). It is felt that the demographics of this population were well represented, as 68% of the 75 total nurses on these units were included in the demographic data

Knowledge and Perception Questionnaire. On the pre-intervention survey, many common misconceptions were identified. The majority of nurses surveyed (72.5%) felt that the term pseudoseizure was appropriate for use and that the condition can be based on clinical history (60.8%). Only 59.6% of nurses indicated that EEG was necessary to confirm diagnosis and 39.2% indicated that they felt that they could differentiate epileptic and nonepileptic spells by witnessing an event. One-third of participants (33.3%) indicated that patients with PNES are “fakers”. Most nurses correctly identified counseling and therapy as the appropriate treatment (80.4%). The survey indicated that only 23.5% of nurses felt that

patients accept the diagnosis. Overall, nurses scored themselves with a low level of self-perceived competency in caring for patients with PNES (mean = median = mode = 5).

Many of the misconceptions noted on the pre-intervention survey were changed on the post-intervention survey. The majority of nurses (67.6%) identified after the education that the term pseudoseizure was not appropriate for use. More nurses also identified that they disagreed that a diagnosis can be made based by witnessing a spell. Post-intervention 85.7% of nurses recognized that EEG is necessary for diagnosis and 94.3% (compared to 56.9%) of nurses indicated that they felt that witnessing a spell could not confirm a diagnosis of PNES.

Prior to the intervention 33.3% of nurses indicated that they felt that patients are “fakers”. After the education intervention, none of the participants indicated that patients are “faking” and indicated that spells occur involuntarily. Participants indicated a significant

Table 5. Definition and Scoring of IPQ-R Subscales

IPQ-R Subscale	Score Range	Definition	Interpretation of High Scores
Time line (acute/chronic)	6-30	Evaluates longevity of condition	Condition will have long duration
Time line (cyclical)	4-20	Evaluates views of critical nature of condition	Condition is cyclic
Consequences	6-30	Evaluates views on negative consequences for patient and family	Condition has great effect on patient and family
Personal control	6-30	Evaluates views on the effect of personal control by the patient of the condition	Patient had high level of control over condition
Treatment control	5-25	Evaluates views on the effectiveness of treatment available for the condition	Treatment is effective
Illness coherence	5-25	Evaluates the understanding of the condition	Greater understanding of the condition
Emotional representations	6-30	Evaluates how the condition affects the person emotionally	Greater emotional impact on patient
Psychological causal attributions	3-30	Evaluates how far psychological causes for the disorder are endorsed	Greater endorsement of psychological causes
Nonpsychological casual attributions	12-60	Evaluates how far non psychological causes for the disorder are endorsed	Greater endorsement of non psychological causes

change in scores indicating that PNES is more common is women and that antiepileptic medications should be stopped. Post-intervention there was a significant ($p= 0.000$) increase in self-perceived competency with a mean score of 6.8, median of 7, and mode of 8.

The range of scores still varied from 1 to 10. Questions number 2, 6, 7, 10, 11, 12, 13, 14 and 16 did not have a significant change in scores (Appendix E).

Illness Perception Questionnaire-Revised. IPQ-R subscales were evaluated based on the tools' author's definitions. Participants did not endorse high scores (more strongly endorse) on any of the subscales. For the two sub-scales that evaluate the cyclic nature of the condition, Time-line (acute/chronic) and Time-line (cyclic) nurses indicated scores in the middle of the range. Participants scored a mean score of 21/30 on Consequence, indicating that nurses do feel that the disorder has some negative consequences on the patient and family. Nurses scored 16/30 indicating that patients have some amount of personal control over their symptoms and a 14/25 for treatment control, evaluating if the condition is treatable. Illness coherence represents the nurses' own understanding of the condition. Nurses scored a mean score of 15/25 in this subscale. Participants scored 22/30 for emotional representations, which represents how strongly the nurses felt that the condition impacts the patients. Nurses did endorse psychological causes more strongly than nonpsychological cause attributes with a mean psychological attribution score of 22.9/30 as compared to 36/60 for nonpsychological causes.

Only three of the subscales changed post intervention. Nurses indicated a decreased score on the time-line (acute/chronic) subscale indicating that nurses were less likely to feel that the condition will last a longer time than they indicated pre-intervention. Nurses also indicated a significant decrease in illness coherence, indicating that they were less likely to endorse understanding of the disorder than pre-intervention. Nurses also indicated a decrease in nonpsychological cause attributes, indicating they were less likely attribute nonpsychological causes for PNES than pre-intervention (Appendix E).

Qualitative Data. Participants were asked to list the three most important causes in ranked order of PNES. On the pre-intervention questionnaires participants indicated that

stress, worry or the patient's emotional state was the most important causes. Stress, worry or emotional state was also ranked as the second and third most important causes. The patient's personality, personal behavior, attitude, or coping skills were the second most frequent response for the first, second and third most important cause of PNES. The third most frequent response was PTSD, accident or injury. Other frequent responses for causes of PNES included drugs or alcohol and hereditary.

Post intervention, stress, worry and emotional state were also identified as most important case of PNES. The second leading theme for most important case for PNES was PTSD, accident, or injury. The second most important cause of PNES were ranked as stress, worry or emotional state, followed by PTSD, accident or injury, and lastly, by personality, behavior, attitude and coping skills. The third ranked most important causes of PNES was stress, worry and emotional state. Participants equally identified personality, behavior, attitude or coping skills, mental illnesses, PTSD, accident or injury or a physiological cause second most frequently as the third most important cause of PNES. The overall most frequent responses for causes of PNES post intervention were stress, worry or emotional state, followed by PTSD, accident or injury and then personality, behavior, attitude or coping skills.

VI. Conclusion and Recommendations

Conclusion

This project reveals that there is a substantial knowledge deficit about psychogenic nonepileptic spells among inpatient neurology nurses at Grant Medical Center. Pre-intervention, nurses indicated many misconceptions, including that one-third of nurses felt that patients with PNES are faking their symptoms. Many nurses felt that spells could be diagnosed by witnessing a spell, by observing certain behaviors, or by clinical history. The majority of nurses identified the term "pseudoseizure" as appropriate use, as is consistent

with previous healthcare provider studies despite experts recommending terminology that is less stigmatized and pejorative (Sahaya et al., 2012; Shneker & Elliott, 2008).

The IPQ-R identified some important information about the perceptions of the participants about patients with PNES. Nurses did not endorse strong feelings on the IPQ-R subscales, rarely marking “strongly agree” or “strongly disagree” on individual scores. This may reflect insecurities among participants about how they feel about patients with PNES. Scores on the IPQ-R indicated that nurses did not feel that they have a strong understanding of the disorder and a low rating of self-perceived competency with a mean of 5 out of 10. Although nurses did acknowledge that the disorder has consequences for the patient and family and that the disorder has an emotion impact on the patient, these subscales were not strongly represented. Nurses indicated that they did not feel that there were effective treatments available. They scored in the middle range to evaluate if patients have personal control of their symptoms. Nurses endorsed psychological attributions slightly more often than nonpsychological attributions. Psychological attributions such as stress, anxiety, personality, and behavior were strongly endorsed as the most important causes on the qualitative portion of the IPQ-R.

After a brief 30-minute education intervention there were improvements in the knowledge and perception scores of participants. One of the most notable changes was that all of the nurses identified that spells occur involuntarily after the education intervention. Only 22.9% felt that the term pseudoseizure was appropriate for use post-intervention. Nurses also recognized appropriate clinical diagnosis and treatment plans.

There was an increase from 41.2 to 65.7% of nurse that recognized that clinical history is not sufficient to diagnosis PNES, however this was not a significant change ($p=0.253$). Nurses also did not have significant changes in questions regarding recognizing that it was not appropriate to induce events, the use of prolactin levels to confirm diagnosis, and

that patient with PNES spells can also have epileptic spells. Although there were positive changes in scores in all of these questions, nurses scored well in these areas pre-intervention. A more significant change may have been noted with a larger sample size. Pre-intervention 80.4% of nurses recognized that the best treatment for PNES is counseling and therapy. This improved to 91.4% post intervention with only 3 participants indicating medication over counseling. Again, this result was not significant at the 95% CI.

There was not a significant change in recognizing the referral process post-intervention. Both pre- and post- intervention, most nurses recommended a neurology referral most commonly, followed by a referral to a psychiatrist. Nurses also did not have a significant change in recommending driving privileges. Driving privileges was not discussed in the education intervention because recommendations for driving vary. One study reported that 49% of epileptologists recommended restricted driving, making the recommendation hazy (Benbadis, Blusten, & Sunstad, 2000). This decision should be deferred to the individual patient's medical treatment team. There was not a significant change in questions regarding the percentage of patients that get better. This question was proposed to gauge the nurses' perception of the treatability of the disorder and was also not specifically addressed in education. Pre- and post- intervention about half of nurses felt that 26-50% of patients get better. Pre- and Post- intervention nurses felt that most patients do not accept the diagnosis.

Nurses indicated a significant improvement in self-perceived competency with a mean score increase from 5 to 6.8. ($p=0.000$) Despite the self-reported increased score in perceived competence, IPQ-R scores reflected that nurses felt that they do not understand the condition well. This is likely a reflection of a better understand of how complex the disorder is post-intervention. Post-intervention, nurses felt that the condition was less

chronic in duration and nurses were less likely to endorse nonpsychological causes on the IPQ-R.

The importance of ruling out physiological causes of nonepileptic before establishing a psychogenic diagnosis was discussed in the education. This may have confused some participants. Physiological causes of nonepileptic spells that were discussed in the education intervention were listed as responses in the post-intervention questionnaires as the most important causes of PNES that were not noted pre-intervention. Although the education may have confused this point, questionnaires still indicated a significant decrease in the endorsement of nonpsychological causes, a similar representation of psychological causes and the causes discussed in the education such as psychological stressors and post traumatic stress disorder were more strongly endorsed by participants post-intervention.

Recommendations

This project demonstrates a need for formal education for inpatient nurses that care patients with PNES. There are currently no formal education or evidence-based nursing guidelines for how to care for a patient with PNES while they are hospitalized. Nurses in this project demonstrated a knowledge deficit and low self-perceived competency in understanding about the condition and how to care for these patients. To foster an environment of health promotion, nurses must be knowledgeable and confident in their skills (Pender et al., 2011). The low level nursing experience and lack of specialty experience of this population may contribute to the knowledge deficits and low levels of self-perceived competence. Evidence-based protocols and guidelines would instill confidence and promote best practice care for patients with PNES.

Healthcare providers can develop strong opinions about patients with PNES. Limited information is available about the opinions of the nurses involved in the care for

these patients despite the close interactions that nurses have with these patients. Further studies are indicated to evaluate the perceptions, knowledge, and influence of education interventions in nurses in other areas that care for patients with PNES. Nurses in areas such as medical-surgical units and nurses in the emergency room that often come in contact with these patients should be evaluated.

In this project, the post-intervention questionnaires were implemented immediately after the education intervention. Further longitudinal evaluation to determine if the intervention was effective is indicated. The use of qualitative questionnaires with open-ended questions or interviews could better capture information about nursing experience and some of the true feelings that nurses have about caring for patients with PNES. Further studies are indicated to determine if nursing interactions were influenced by improved nursing perceptions and knowledge and if this improved patient engagement in treatment plans.

Limitations

The use of convenience sampling creates the risk of sampling error. With convenience sampling there is risk of not equally representing the entire population (Terry, 2012). Efforts were made to including all of the available staff in the project to get most accurate representation of the population. There were a total of 51 participants out of the 75 available staff (68%). Some participant drop out between the pre- and post- surveys was anticipated. The participant drop out rate was higher than expected at 31% with 35 of the original 51 participants continuing for the duration of the project. The high level of participant drop out was attributed to the short time frame allotted for the project. Not all participants were at the follow up staff meetings due to weather, work schedule conflicts and other circumstances. There was not enough time in the project period to hold additional meetings. External validity is not important in translational science because

generalizations are not being made back to a population from which subjects were selected. The reader is free to review demographics to assess if the findings in this project are applicable to their practice.

Additionally, the second questionnaire chosen, the Knowledge and Perception Questionnaire that is adapted from the Shneker and Elliot study (2008) is not a validated tool. Currently there is not a standardized tool available to obtain this data. A standardized, evidence based tool or program would provide more validity and control for the project. After an extensive literature, an existing education tool that meets the objectives of this project was not identified. Evidence based guidelines were used to develop an education intervention to meet the objectives identified for the purpose of this project.

There were some missing data on some of the surveys. On the IPR-Q, subscales cannot be accurately assessed without responses to all questions in the subscale. Portions that were left blank were not scored. The amount of data collected during this study may have contributed to participant fatigue. Some of the participants attended staff meetings at the end of their shift, which likely contributed to participant fatigue.

VII. Summary

Healthcare providers have been noted to have negative illness perceptions of patients with PNES in multiple studies and this project is no exception. Negative healthcare provider illness perceptions are noted to be a barrier to patient outcomes in other stigmatized conditions, but the link to negative healthcare provider perceptions and patient outcomes with PNES has not been well studied. Poor knowledge or negative attitudes about a diagnosis can inhibit a providers' communication with a patient. According to Pender's health promotion model, nurses must be confident and knowledgeable in order to foster an environment to promote health promotion behaviors. This project demonstrated that the

inpatient neurology nurses at Grant Medical Center had low levels of self-perceived competency and were not knowledgeable about PNES.

After a brief education intervention nurses had improved knowledge, self-perceived competency, and some nursing perceptions. Further evaluation is indicated to determine the long-term influences of a brief education intervention, and to determine the perceptions and utility of education in other nursing populations. Further evaluation indicated to determine if improving nursing knowledge and perceptions enhances therapeutic nursing interactions to help patient's achieve their healthcare goals. Larger studies are indicated to determine the influence of intervention to improve nursing knowledge and perception on patient engagement in treatment and patient outcomes.

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Appendix A. Survey Cover Letter**OHIOHEALTH****SURVEY COVER LETTER**

TITLE OF STUDY: Nursing Perceptions of Patients with Psychogenic Nonepileptic Spells: Improving Patient Outcomes

PRINCIPAL INVESTIGATOR: Amanda Cramer MSN, RN, CNP, CNRN

You are being asked to take part in a research project to describe the nursing perception of patients with nonepileptic spells with an education intervention to improve nursing knowledge and perception of this patient population. The project is being conducted by Amanda Cramer, from OhioHealth, neurology nurse practitioner. Amanda is completing this study as part of the Doctor of Nursing Practice program at Otterbein University. Dr. John Chovan at Otterbein University is the project advisor and Sub-Investigator. The research will help us understand the nursing relationship with patients with psychogenic nonepileptic spells and how this relationship can influence patient outcomes.

You will be asked to complete two short questionnaires and a brief demographics questionnaire. The first questionnaire, the Illness Perception Questionnaire-Revised is designed to evaluate the illness perception of patients with nonepileptic spells. The second questionnaire is designed to evaluate knowledge and self described competency of caregivers of patients with nonepileptic spells. Completion of these questionnaires will take approximately 15 minutes. These will be offered during a unit staff meeting. You will also be asked to attend a 30-minute education session at the next staff meeting. You will be asked to complete the same two questionnaires and demographics questionnaire a second time after the education session. This will take an additional 45 minutes (30 minutes for education and 15 minutes to complete the questionnaires). Your participation is voluntary. If you do not wish to take part, simply discard the questionnaires. You can refuse to answer questions that you do not wish to answer. You can decide to withdraw from the study at any time without penalty or repercussion.

Responses will be completely anonymous and kept confidential; your name will not appear anywhere on the survey. You have received two copies of the Survey Cover Letter. Signing and returning one copy of the cover letter confirms your consent to take part in the study. Keep the second copy of the cover letter for your records.

If you have any questions regarding the research, contact Amanda Cramer at (614) 566-7606 or Dr. John Chovan at (614) 823-1526. If you have any questions regarding your rights as a research subject, please contact Dr. Randall Franz, Chair of the OhioHealth Institutional Review Board #2 at (614) 566-4431. This office oversees the review of the research to protect your rights and is not involved with this study.

Thank you again for your help,

Amanda J. Cramer MSN RN CNP CNRN

Principal Investigator

Doctor of Nursing Practice Student

amanda.cramer1@otterbein.edu

614-566-7606 (office) or 614-657-8274 (cell)

John D. Chovan PhD DNP RN CNP CNS

Sub- Investigator

Assistant Professor & Director,

DNP Program

614-823-1526 (Office)

Signature: _____ Date: _____

Signature of subject agreeing to participate with my signature I affirm that I am at least 18 years of age.

Appendix B. Instruments**ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)**

Please indicate how much you agree or disagree with the following statements about patients who experience psychogenic nonepileptic spells (PNES) by ticking the appropriate box.

	VIEWS ABOUT ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	The illness will last a short time					
IP2	The illness is likely to be permanent rather than temporary					
IP3	The illness will last for a long time					
IP4	This illness will pass quickly					
IP5	Patient's will have spells for the rest of their lives					
IP6	PNES is a serious condition					
IP7	PNES has major consequences on the patient's life					
IP8	PNES does not have much effect on the patient's life					
IP9	PNES strongly affects the way others see the patient					
IP10	PNES has serious financial consequences					
IP11	The illness causes difficulties for those who are close to the patient					
IP12	There is a lot that the patient can do to control their spells					
IP13	What the patient does can determine whether their spells gets better or worse					
IP14	The course of the illness depends on the patient					
IP15	Nothing the patient does will affect their spells					
IP16	Patients have the power to influence their illness					
IP17	Patients' actions will have no affect on the outcome of their illness					
IP18	Spells will improve with time					
IP19	There is very little that can be done to improve spells					
IP20	Treatment will be effective in curing spells					

IP21	The negative effects of spells can be prevented (avoided) by treatment					
IP22	Treatment can control spells					
IP23	There is nothing which can help the condition					
IP24	The symptoms of the condition are puzzling to me					
IP25	Spells are a mystery to me					
IP26	I don't understand spells					
IP27	The illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of the condition					
IP29	The symptoms of the illness can change a great deal from day to day					
IP30	Spells can come and go in cycles					
IP31	The illness is very unpredictable					
IP32	The illness goes through cycles where it is better and worse					
IP33	Patients with PNES are depressed					
IP34	Patients with PNES are upset					
IP35	PNES makes patients feel angry					
IP36	Patients with PNES are worried about their illness					
IP37	Patients with PNES are anxious about their illness					
IP38	PNES makes patients feel afraid					

CAUSES OF THE ILLNESS

We are interested in what you consider what might be the cause of patient's PNES. Please indicate how much you agree or disagree with the causes by ticking the appropriate box.

	POSSIBLE CAUSE	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary- it runs in the family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in the past					
C7	Pollution in the environment					
C8	Patient's own behavior					
C9	Patient's mental attitude (thinking about life negatively)					
C10	Family problems or worries caused by illness					
C11	Overwork					
C12	Patient's emotional state (feeling down, lonely, anxious, empty)					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe cause PNES. You may list any of the items from the box above or you may have additional ideas of your own.

The most important causes of PNES:

1. _____
2. _____
3. _____

Moss-Morris, R., Weinman, K., Petrie, K. J., Horne, R., Cameron, J. D., Buick, D. (2002). The revised illness perception study questionnaire (IPQ-R). *Psychological Health*, 17, 1-16.

Pseudoseizure Questionnaire (adapted from Shneker & Elliott, 2008)

1. The term pseudoseizures is
 - a. Appropriate for use
 - b. Not appropriate for use
2. Pseudoseizures can be diagnosed based on clinical history
 - a. Disagree/somewhat disagree
 - b. Agree/somewhat agree
3. I can differentiate pseudoseizures from epileptic seizures once I witness the event
 - a. Disagree/somewhat disagree
 - b. Agree/somewhat agree
4. Diagnosis of pseudoseizures must always be confirmed by video-EEG monitoring
 - a. Agree
 - b. Disagree- clinical diagnosis can be sufficient
 - c. Video EEG is needed only when clinical diagnosis is not clear
5. Inducing the patient's events at bedside by suggestion or doing certain maneuvers confirms that the events are pseudo seizures
 - a. Agree
 - b. Disagree
6. If I can, I try to induce an event
 - a. No
 - b. Yes
7. If prolactin level is not elevated in patient with a spell, this confirms pseudoseizure
 - a. Agree
 - b. Disagree
 - c. A patient's prolactin level does not affect my diagnosis
8. Most pseudoseizures are
 - a. Voluntarily induced (patients are fakers)
 - b. Occur involuntarily
9. Pseudoseizures occur more commonly in
 - a. Men
 - b. Woman
 - c. Occurs equally in men and woman

10. Persons with pseudoseizures can also have epileptic seizures
 - a. Agree
 - b. Disagree
11. Patient's with suspected pseudoseizures should first be referred to a:
 - a. Neurologist
 - b. Psychiatrist
 - c. Psychologist
 - d. No referral
12. The best treatment for pseudoseizures is
 - a. Medications
 - b. Counseling and therapy
13. Patients with pseudoseizures must have their driving privileges restricted similar to patients with epileptic seizures.
 - a. Agree
 - b. Disagree
14. The percentage of patients with pseudoseizures that get better is:
 - a. ≥ 25 percent
 - b. 26-50 percent
 - c. ≥ 51 percent
15. When a patient with pseudoseizures is taking antiepileptic drugs (AEDs) for pseudoseizures:
 - a. AEDs should be stopped
 - b. AEDs should be continued
16. Most of my patients when confronted with a diagnosis of pseudoseizures:
 - a. Accept the diagnosis
 - b. Do not accept the diagnosis
17. How confident are you in dealing with a patient with pseudoseizures?
(Graded from 1 to 10: 1=poor, 10 = excellent)

Adapted from:

Shneker, B. J., Elliott, J. O. (2008) Primary care and emergency physician attitudes and beliefs related to patients with psychogenic nonepileptic spells. *Epilepsy and Behavior* 13, 243-247.

Demographics Survey

Please complete the demographic information below.

Gender	Male	Female			
Years in practice	1-5	6-10	>10		
Years in practice with neurology patients	1-5	6-10	>10		
Education level	ADN	BSN	MSN	DNP or PhD	Other post graduate degree
Do you have a neurology specialty certification	Yes	No			
Have you had special training in epilepsy or PNES in the past 5 years	Yes	No			

Appendix C. Education Intervention

NURSING CARE FOR THE PATIENT WITH PSYCHOGENIC NONEPILEPTIC SPELLS

Amanda Cramer RN, MSN, CNP, CNRN
Neurology Nurse Practitioner, Grant Medical Center
Doctor of Nursing Practice Student, Otterbein University

Autumn 2015

Objectives

- Define Psychogenic Nonepileptic Spells (PNES)
 - Describe evidence based diagnoses and treatment
- Describe evidence-based guidelines for patient communication regarding PNES
- Describe inpatient-nursing interventions for PNES
- Address common misconceptions associated with PNES

Nonepileptic Spells

- Involuntary episodes that briefly change a person's behavior and often look like a epileptic seizure
- Not all non-epileptic spells are psychogenic. Some physiologic causes:
 - Cardiogenic
 - Sleep apnea/hypoxia
 - Endocrine
 - Adrenal
 - Carcinoid
 - Mixed Epilepsy

Psychogenic Nonepileptic Spells

- Subset of conversion disorder caused by a psychological conflict rather than a physiologic cause
 - Patients are not aware of producing symptoms
 - Rarely malingering or factitious
- As disabling as epilepsy
- No alteration in electrical brain activity on EEG associated with spells.
- Associated with high rates of patient disability

Psychogenic Nonepileptic Spells

- Accounts for 12-18% of patients that present with altered consciousness to ED or neuro clinics
- Accounts for 20-40% of patients evaluated in epilepsy units
- Frequently misdiagnosed
 - 91% of patients are started on an AED at some point
- Who has PNES-
 - 70-90% more common in females, males less likely to report
 - Age 18-40
 - Can occur in young children (better prognosis) and the elderly

Etiology

- Strong correlation with history of traumatic events
 - 77% history of sexual abuse, 70% physical abuse, 70% childhood trauma (reported 99-100% of patients have history of PTSD in some studies)
- Also associated with depression, anxiety, dissociation, personality disorders
 - 70% have a comorbid psychological condition
 - Note that patients with epilepsy also have a high rate of depression and other psychiatric comorbidities.
- Concomitant diagnosis of epilepsy
 - Complicated to treat- differentiating spells and treatment plan
 - About 15% of patients

Outcomes

- Overuse of healthcare resources
 - Comparable to treatment cost of intractable epilepsy at an estimated \$231,432/patient/year
 - Cost decreases once a diagnosis is established
- High rate of unemployment (as high as 79%)
- As disabling as epilepsy
- Lower quality of life scores than epilepsy patients
- Social Stigma- social and personal problems
- At 5 years after diagnosis, 60% continue to have spells

Outcomes

- Patient's have improved outcomes with reduced frequency and intensity of spells and improved quality of life when they engage in treatment recommendations for PNES.
- 60-70% of adult patients have elimination of spells. Children have a higher success rate

Diagnosis

- Average of 5-7 year delay from symptom onset to diagnosis
- Diagnosis cannot be made based on observing a spell
- Prolactin levels- nondiagnostic
- Long Term Video EEG is the gold standard. Goal is to record several events to confirm "target event"
- Epilepsy Monitoring Unit- Provoke seizures/spells in a controlled environment
- Rule out physiological causes
- Behavioral health referrals

Treatment

- Treatment goal is to eliminate spells and improve quality of life
- Begins with careful discussion of the EEG results- usually by the neurologist
- Medications (AEDs, SSRIs)
 - AEDs have toxic side effects, can exacerbate symptoms
 - AEDs often weaned by the neurologist after diagnosis is established
 - SSRIs may be useful in managing stress symptoms, not effective for treating PNES alone.
- Cognitive Behavioral Therapy- reduces spell frequency/ intensity and improve quality of life scores

Barriers to treatment

- Delayed diagnosis: 80 percent of patients are diagnosed as epileptic first
 - Patients often told that they have had abnormal EEGs by a non-specialist
- Many patients continue to believe that there is a physiological cause for their symptoms
- Less than half of patients engage in recommend treatment
- Patients report feeling that they are perceived as "faking" or "being crazy"

Barriers to Treatment

- Negative healthcare provider perceptions- linked to decreased patient engagement in diagnosis
- Care provider knowledge base- lack of referral/ recognition of diagnosis process
- Access to epilepsy monitoring facilities
- Access to treatment
 - Available providers, uninsured or underinsured, not appropriately referred
- Supportive psychotherapy alone- not sufficient

How can I make a difference?

- When patients accept the diagnosis and engage in evidence based care, research shows patients can have a reduced frequency and intensity of seizures and an increased quality of life.
- Nurses are a key member of the healthcare team in promoting health behaviors
- Studies show that patient engagement in diagnosis and treatment improves with effective communication and education about the diagnosis

Patient communication

- Effective communication about the diagnosis improves patient engagement and patient outcomes
- Avoid using stereotyped terminology such as “fake seizure”, “Pseudoseizure”, “Hysterical Seizure”
- Never refer to a patient as faking or intentionally causing symptoms
- Reinforce to the patient that they are not “crazy”. This is a real, treatable condition.
- Remember that these spells are something that happen to the patient, not something symptoms that they intentionally produce
- Ohiohealth Patient Education Pamphlet available online

During a Spell

- Keep the patient safe, maintain seizure precautions per hospital protocol (siderail protectors ect).
- Do not force anything in the patients mouth or perform painful stimulation
- Document the spell (Onset, behavior, duration, vitals)
 - Press the marker if the patient is on V-EEG
- Reassure patient and family that the patient is safe
- Notify the physician
- Benzodiazepines (lorazepam, diazepam ect) are typically not given for non-epileptic spells. These are not effective and have dangerous side effects. Discuss with the patient's physician if you have questions.

Common misconceptions

- Patient is “faking”, intentionally producing symptoms for attention
- A practitioner can diagnose a nonepileptic event by witnessing the spell
- Prolactin levels can be used to make a diagnosis of epileptic vs. nonepileptic spells
- All spells in patients with psychiatric disorders are nonepileptic
- All nonepileptic spells are psychogenic

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Appendix D. Data Tables

IPQ-R Scores Pre Intervention

Variable	Time line <i>acute/ chronic</i>	Time line <i>cyclical</i>	Consequences	Personal control	Treatmen t control	Illness coherence	Emotional representation	Psychological causal attributions	Non- psychological casual attributions
Score Range	6-30	4-20	6-30	6-30	5-25	5-25	6-30	6-30	12-60
Survey 1	8	10	22	21	14	10	19	17	39
Survey 2	10	16	19	16	14	13	18	32	32
Survey 3	18	12	21	11	14	16	21	17	40
Survey 4	20	16	21	12	12	18	20	20	41
Survey 5	19	16	26	20	13	17	24	23	37
Survey 6	20	16	23	23	12	8	25	23	37
Survey 7	19	16	21	19	14	10	24	20	18
Survey 8	20	13	23	19	14	22	24	24	40
Survey 9	20	16	22	16	14	21	22	24	46
Survey 10	16	16	22	16	15	13	26	29	31
Survey 11	17	16	17	18	12	10	24	18	36
Survey 12	17	15	22	17	14	15	24	22	28
Survey 13	15	10	20	20	14	10	16	24	28
Survey 14	15	16	21	14	15	18	21	22	42
Survey 15	18	16	22	14	9	19	24		
Survey 16	16	16	18	18	17	16	23	25	40
Survey 17	17	16	21	19	14	16	21	16	38
Survey 18	16	16	21	20	15	15	24	24	28
Survey 19	13	15	22	18	14	16	22	22	40
Survey 20	16	13	24	19	14	16	22	24	34
Survey 21	16	13	22	15	14	15	19	20	36
Survey 22	13	16	19	15	12	18	16	16	40
Survey 23	17	16	22	14	16	14	24	24	31
Survey 24	18	14	19	14	12	15	24	26	41
Survey 25	18	18	16	18	16	18	24	28	36
Survey 26	15	16	20	14	16	22	24	22	30
Survey 27	18	13	23	12	14	13	24	20	38
Survey 28	19	16	21	12	14	19	24	22	38
Survey 29	21	13	21	10	16	14	28	25	42
Survey 30	20	16	22	20	13	18	21	16	36
Survey 31	18	12	18	18	15	15	18	18	36
Survey 32	17	15	19	18	15	11	20	24	38
Survey 33	20	4	25	17	17	10	14	27	31
Survey 34	16	12	20	18	16	12	18	25	40

IPQ-R Scores Pre Intervention

Variable	Time line <i>acute/ chronic</i>	Time line <i>cyclical</i>	Consequences	Personal control	Treatment control	Illness coherence	Emotional representation	Psychological causal attributions	Non- psychological casual attributions
Score range	6-30	4-20	6-30	6-30	5-25	5-25	6-30	6-30	12-60
Survey 35	17	12	22	17	15	17	24	16	40
Survey 36	16	16	20	14	16	14	23	25	27
Survey 37	20	17	22	15	14	11	21	25	38
Survey 38	23	16	26	19	13	15	30	30	48
Survey 39	17	18	19	22	12	20	24	16	28
Survey 40	17	16	18	22	14	18	19	27	39
Survey 41	17	14	24	16	14	17	24	29	27
Survey 42	20	16	17	15	10	10	20	24	43
Survey 43	18	16	22	23	13	15	24	24	36
Survey 44	15	17	23	18	16	13	27	26	27
Survey 45	15	14	23	17	15	18	21	23	39
Survey 46	20	18	17	18	12	18	24	22	40
Survey 47	17	15	22	18	12	16	24	22	36
Survey 48	19	16	21	20	17	15	23	23	38
Survey 49	16	16	25	16	15	14	20	24	44
Survey 50	14	16	26	16	12	16	21	26	33
Survey 51	19	17	21	20	14	16	23	22	33
Median	17	16	21	18	14	15	23	23.5	37.5
Interquartile range	3	2	2	4	2	4.75	3.5	4.5	7.75

IPQ-R Qualitative Data Pre-Intervention Survey			
Survey 1	Stress or worry	Patient's own behavior	Patient's emotional state
Survey 2	Patient's emotional state	Stress and worry	Alcohol
Survey 3	Stress and worry	Family Problems	Overwork
Survey 4	Hereditary	Accident or injury	Aging
Survey 5	Stress or worry	Patient's emotional state	Personality
Survey 6	Patient's own behavior	Stress and worry	Patient's emotional state
Survey 7	Emotional disturbance	Stress	Poor coping abilities
Survey 8	Overwork	Stressors	Patient's emotional state, severe anxiety
Survey 9	Stress or worry	Poor medical care in the past	Hereditary
Survey 10	Altered immunity	Poor medical care in the past	Alcohol
Survey 11	Stress	Eating habits	Alcohol
Survey 12	PTSD	Depressed/Anxiety	Stress
Survey 13	Patient's own behavior	Mental attitude	Family problems or worries
Survey 14	Stress	Hereditary	Germs or virus
Survey 15	Stress	Emotions	Accident
Survey 16	Stress	Medication	Depression
Survey 17	Psychological issues		
Survey 18	Patient's mental attitude	Stress or worry	Patient's own behavior
Survey 19	Patient's own behavior	Patient's mental attitude	Stress or worry
Survey 20	Patient's personality	Emotional state	Mental attitude
Survey 21			
Survey 22	Patient's mental behavior	Family Problems	Personality
Survey 23	Stress or worry	Accident or injury	Worries caused by illness
Survey 24	Hereditary	Alcohol	Accident or injury
Survey 25	Patient's own behavior	Emotional state	Mental attitude
Survey 26	Stress	Emotional state	Accident
Survey 27	Accident or injury	Poor medical care in the past	Hereditary
Survey 28	Stress or worry	Worries caused by illness	Patient's emotional state, anxiety
Survey 29	PTSD		

IPQ-R Qualitative Data Pre-Intervention Survey			
Survey 30	Stressors	Mental illness	Environment/Drugs
Survey 31			
Survey 32	Patient's emotional state	Stress or worry	Overwork
Survey 33	Patient's emotional state	Patient's own behavior	Stress or worry
Survey 34	Stress	Family Problems	Patient's emotional state
Survey 35	Stress or worry	Overwork	Accident or injury
Survey 36	Stress	Overwork	Emotional state
Survey 37	Stress	Personality	Negative attitude
Survey 38	Psychological issues		
Survey 39	Patient's own behavior	Patient's emotional state	Personality
Survey 40	Patient's own behavior	Alcohol	Drugs
Survey 41	Patient's mental attitude	Patient's own behavior	Patient's emotional state
Survey 42	Unknown	Emotional state	Accident or injury
Survey 43	Stress, sickness, anxiety	Poor medical care in the past	Personality or mental attitude
Survey 44	Patient's emotional state	Patient's mental attitude	Stress or worry
Survey 45	Emotional state of patient	Family Problems	Accident or injury
Survey 46			
Survey 47			
Survey 48			
Survey 49	Emotional state	Stress	Family problems
Survey 50	Family problems or worry caused by illness	Patient's emotional state	Stress or worry
Survey 51	Patient's own behavior	Patient's emotional state	Accident or injury

Knowledge and Perception Pre-Intervention Survey

Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Survey 1	a	a	b	b	a	a	b	a	b	a	a	b	b	b	a	b	10
Survey 2	a	b	b	a	b	a	c	b	c	a	a	a	b	b	a	b	2
Survey 3	a	b	a	c	b	a	c	b	a	b	b	b	b	c	b	a	1
Survey 4	b	b	b	a	a	b	b	b	b	a	a	a	a	c	b	b	2
Survey 5	a	b	a	b	a	a	b	a	c	b	b	b	a	a	a	b	2
Survey 6	b	a	a	a	b	b	b	a	b	a	a	b	a	a	a	b	8
Survey 7	a	a	a	a	a	b	c	b	b	b	c	b	a	c	a	b	9
Survey 8	b	b	a	a	a	a	a	a	c	a	a	b	a	b	a	b	3
Survey 9	a	b	b	a	a	a	b	b	b	a	a	b	a	b	a	b	3
Survey 10	a	b	b	a	a	a	c	b	c	a	a	a	a	b	b	b	4
Survey 11	a	b	b	a	b	a	b	b	a	a	a	b	a	a	a	b	5
Survey 12	a	b	a	a	a	a	c	b	b	a	b	b	a	b	a	b	3
Survey 13	a	b	a	a	b	a	c	b	b	b	a	a	b	a	a	b	5
Survey 14	b	a	a	a	b	a	c	b	c	a	a	b	a	b	b	b	5
Survey 15	a	b	a	c	a	a	b	a	b	a	a	b	a	c	a	b	6
Survey 16	a	b	a	b	b	a	b	b	c	a	a	b	a	b	b	b	7
Survey 17	a	a	a	a	b	a	c	b	b	b	a	b	a	a	a		1
Survey 18	a	b	b	c	b	a	c	b	c	a	a	b	a	a	a	a	7
Survey 19	a	b	b	a	a	a	b	a	c	a	a	b	a	b	b	b	6
Survey 20	a	b	a	c	b	a	c	a	b	a	a	a	a	b	b	b	5
Survey 21	b	b	b	a	a	a	c	a	b	a	a	b	a	a	a	b	5
Survey 22	b	b	a	c	b	a	b	b	a	a	a	b	a	a	b	a	5
Survey 23	a	a	a	b	b	a	b	b	b	a	a	b	a	b	b	a	5
Survey 24	a	b	b	c	a	a	c	a	b	b	b	b	a	c	b	b	6
Survey 25	b	b	a	a	b	a	c	b	c	a	a	a	a	b	b	b	4
Survey 26	b	b	a	a	b	a	c	b	c	a	a	a	a	b	b	b	4
Survey 27	a	a	b	a	b	a	b	b	a	a	a	b	a	a	b	b	5
Survey 28	b	a	a	c	b	a	c	b	b	a	a	b	a	b	a	b	2
Survey 29	a	b	b	a	a	b	a	b	b	a	a	a	a	a	a	a	
Survey 30	a	b	a	a	a	a	b	a	a	a	a	b	a	a	b	b	6
Survey 31	a	a	a	c	b	a	c	b	b	a	b	b	a	a	a	b	1
Survey 32	a	a	b	a	b	a	c	a	b	a	a	b	a	c	a	a	7
Survey 33	a	a	a	b	a	b	c	b	b	a	a	b	a	c	b	a	8
Survey 34	b	a	a	a	a	b	b	a	b	a	b	b	b	b	a	a	8
Survey 35	a	b	b	b	a	a	c	b	b	a	a	b	a	a	b	b	5
Survey 36	a	b	a	b	a	a	c	b	b	a	a	b	a	c	a	a	5
Survey 37	a	b	b	c	b	a	c	b	b	a	a	b	a	b	a	b	8
Survey 38	b	b	b	a	a	a	b	a	c	a	a	b	a	b	a	b	10
Survey 39	a	a	b	b	b	b	b	a	c	a	a	b	b	b	a	b	5

Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Survey 40	a	a	b	a	a	a	c	a	c	a	b	b	a	a	b	a	2
Survey 41	a	a	b	c	b	a	c	a	c	a	a	b	a	b	a	a	4
Survey 42	b	a	a	a	b	a	c	b	b	a	a	b	b	c	a	b	8
Survey 43	b	b	b	c	b	a	c	b	b	a	a	b	a	b	a	b	5
Survey 44	a	b	a	c	b	a	b	b	b	b	a	b	a	b	a	b	8
Survey 45	a	b	a	a	b	a	c	b	c	a	a	b	a	b	b	b	5
Survey 46	a	a	a	c	b	a	b	b	a	a	a	a	a	c	b	b	3
Survey 47	b	a	a	a	b	a	b	b	b	a	a	b		c	b	b	3
Survey 48	a	b	a	a	a	b	c	a	c	a	a	a	a	b	b	a	3
Survey 49	a	a	a	a	b	a	c	b	b	a	a	b	a	b	b	b	7
Survey 50	a	a	a	b	b	a	b	b	b	a	c	b	a	b	b	b	6
Survey 51	a	a	a	a	a	a	b	b	a	a	a	b	a	a	a	b	1
A	37	21	31	29	22	43	2	17	7	44	42	10	43	15	28	12	
B	14	30	20	9	29	8	21	34	28	7	7	41	7	25	23	38	
C	0	0	0	13	0	0	28	0	16	0	2	0	0	11	0	0	
D	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	

Question # 17	
Range	1-10
Mean	5
Median	5
Mode	5

IPQ-R Scores Post Intervention

Variable	Time line <i>acute/ chronic</i>	Time line <i>cyclical</i>	Consequences	Personal control	Treatmen t control	Illness coherence	Emotional representation	Psychological causal attributions	Non- psychological casual attributions
Score Range	6-30	4-20	6-30	6-30	5-25	5-25	6-30	6-30	12-60
Survey 1	17	12	21	19	13	12	21	20	30
Survey 2	16	13	22	18	16	12	24	24	30
Survey 3	18	9	24	16	14	11	21	24	30
Survey 4	14	15	22	14	10	17	22	24	30
Survey 5	14	15	26	15	13	18	20	31	47
Survey 6	13	16	24	10	15	11	22	20	28
Survey 7	16	15	22	14	14	10	18	24	25
Survey 8	17	15	21	14	14	14	24	22	37
Survey 9	13	14	22	18	13	11	17	24	43
Survey 10	16	16	15	18	17	16	21	24	39
Survey 11	12	12	26	11	17	9	30	24	48
Survey 12	21	20	26	18	13	9	24	30	16
Survey 13	12	14	25	19	14	9	26	22	27
Survey 14	17	16	20	18	14	11	24	20	26
Survey 15	18	16	22	16	14	17	24	18	36
Survey 16	19	15	26	16	17	9	23	26	29
Survey 17	18	16	22	16	18	10	24	22	24
Survey 18	14	16	21	18	14	9	24	25	38
Survey 19	19	16	18	14	13	12	24	24	33
Survey 20	16	18	25	16	11	12	14	23	22
Survey 21	15	18	21	14	11	15	24	20	38
Survey 22	13	16	21	24	14	15	23	22	22
Survey 23	20	13	21	16	16	12	22	24	38
Survey 24	15	16	18	20	16	15	24	27	39
Survey 25	13	11	21	15	13	12	20	16	34
Survey 26	16	14	17	17	16	16	24	20	28
Survey 27	15	13	21	17	18	16	19	24	38
Survey 28	14	13	16	16	12	8	20	18	12
Survey 29	15	16	22	15	15	15	24	22	29
Survey 30	15	16	22	13	15	9	23	21	24
Survey 31	20	14	24	22	16	12	21	25	39
Survey 32	15	16	22	14	14	17	18	20	26
Survey 33	17	15	22	16	12	12	23	24	25
Survey 34	18	20	26	20	13	15	28	24	28

IPQ-R Scores Post Intervention

Variable	Time line <i>acute/ chronic</i>	Time line <i>cyclical</i>	Consequences	Personal control	Treatment control	Illness coherence	Emotional representation	Psychological causal attributions	Non-psychological casual attributions
Score range	6-30	4-20	6-30	6-30	5-25	5-25	6-30	6-30	12-60
Survey 35	20	16	21	19	16	15	22	25	36
Survey 36	21	15	21	19	19	14	20	24	26
Survey 37	10	17	26	15	16	9	23	26	16
Survey 38	17	16	22	16	16	10	24	26	46
Survey 39	15	16	22	15	13	12	24	16	27
Survey 40	18	10	14	20	16	19	23	22	31
Survey 41	18	12	22	18	16	12	19	19	38
Median	16	15	22	16	14	12	23	24	30
Interquartile range	16	15	22	16	14	12	23	24	30

IPQ-R Qualitative Data Post-Intervention Survey			
Survey 1	Past trauma physical	Emotional trauma	PTSD
Survey 2	Stress	Abuse	Anxiety
Survey 3	Stress or worry	Emotional state	Worry
Survey 4	Stress or worry	Family problems or worries caused by illness	Patient's emotional state
Survey 5	Stress	Poor past medical care	Family problems or worries
Survey 6	PTSD	Sleep Apnea	Cardio
Survey 7	PTSD	Depression	Physical Illness
Survey 8	Stress	Family problems	Feeling anxious
Survey 9	Stress	Personality	Patient's own behavior
Survey 10	Stress	Mental attitude	Alcohol
Survey 11	PTSD		
Survey 12	Patient's emotional state	Stress or worry	Family problems or worries
Survey 13	Cardiogenic	Stress	Physical traumatic abuse
Survey 14	Significant life change	Emotional state	Stress
Survey 15	Psychological disorders	Altered immunity	Stress
Survey 16	PTSD	Stress	Psychological
Survey 17	Stress	Anxiety	**
Survey 18	Patient's emotional state	Stress or worry	Patient's own behavior
Survey 19	Anxiety (emotional state)	Overworked	Patient's behavior
Survey 20	Anxiety	Stress	Depression
Survey 21	Trauma	Stress	Illness (Comorbidity)
Survey 22	Patient's mental attitude	Patient's emotional states	stress/worry
Survey 23	Stress-Trauma	Hormonal	Carcinoid
Survey 24	Emotional Stress	Mental Attitude	Overwork
Survey 25	Patient's emotional state	Stress or worry	Accident or injury
Survey 26	PTSD	Sexual Abuse	
Survey 27	PTSD of some sort	Physical/Verbal Abuse	
Survey 28	Patient's emotional state	Patient's mental attitude	Stress or worry
Survey 29	PTSD		

IPQ-R Qualitative Data Pre-Intervention Survey			
Survey 30	Anxiety	Depression	Stress
Survey 31	Patient's emotional state	Patient's mental attitude	Stress or worry
Survey 32	Trauma	PTSD	Depression
Survey 33	Sexual trauma	Child Abuse	Family problems or worries caused by illness
Survey 34	Stress	Anxiety	Misdiagnosis
Survey 35	Stress or worry	Personality	Emotional States
Survey 36			
Survey 37	Sexual/Physical abuse	Comorbidities i.e. epilepsy, depression	Stressors/worrying
Survey 38	Stress or worry	Patient's emotional states	Family problems or worries caused by illness
Survey 39	Cardiogenic	Endocrine	Behavioral Health
Survey 40	PTSD	Psychological Issues	Withdrawal
Survey 41	Sleep Apnea	Endocrine	Cardiogenic

Knowledge and Perception Post-Intervention Survey

Question #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Survey 1	b	a	a	a	b	a	c	b	c	a	b	b	a	b	a	b	7
Survey 2	b	b	a	a	b	a	c	b	b	a	b	b	a	b	a	b	10
Survey 3	a	a	a	a	b	a	b	b	b	a	a	b	a	b	a	a	8
Survey 4	a	a	a	a	b	a	b	b	b	a	a	b	a	b	a	a	6
Survey 5	b	b	a	b	b	a	c	b	b	a	a	b	a	b	b	b	5
Survey 6	b	a	a	c	b	a	c	b	b	a	b	a	b	b	b	b	8
Survey 7	b	a	a	a	b	b	a	b	b	a	b	b	a	a	a	b	1
Survey 8	b	a	a	a	b	a	c	b	b	a	a	b	a	b	a	b	6
Survey 9	b	a	a	a	b	a	b	b	b	a	a	b	a	c	b	b	7
Survey 10	a	b	a	a	b	b	c	b	b	a	a	b	a	c	a	a	5
Survey 11	b	a	a	a	b	a	c	b	b	a	a	a	a	b	a	b	10
Survey 12	a	a	a	c	b	a	b	b	c	a	a	b	a	b	b	b	8
Survey 13	b	a	a	a	b	a	b	b	b	a	a	b	a	a	a	b	8
Survey 14	b	b	a	a	b	a	c	b	b	a	a	b	b	b	a	b	8
Survey 15	b	b	a	c	b	a	c	b	b	a	a	b	a	a	a	b	5
Survey 16	b	b	a	a	b	a	c	b	b	a	a	b	b	b	a	b	9
Survey 17	b	a	a	a	b	b	c	b	b	a	a	b	b	a	a	b	10
Survey 18		a	a	a	a	a	c	b	b	a	a	b	a	c	b	a	8
Survey 19	b	a	a	a	b	a	b	b	b	a	a	b	a	a	a	b	8
Survey 20	a	a	a	a	b	a	c	b	b	a	a	b	b	b	a	b	6
Survey 21	b	b	a	a	b	a	c	b	b	a	a	b	a	b	a	b	7
Survey 22	b	a	a	a	b	a	b	b	b	a	a	b	a	b	a	b	7
Survey 23	b	a	a	a	b	a	c	b	b	a	a	b	a	b	a	b	8
Survey 24	b	b	a	a	b	a	c	b	b	a	a	b	a	a	a	b	7
Survey 25	a	a	a	a	b	a	c	b	b	a	a	b	b	c	a	b	8
Survey 26	b	a	a	a	b	a	b	b	b	a	a	b	b	c	a	b	8
Survey 27	b	b	a	a	b	a	c	b	b	a	a	b	a	b	a	a	4
Survey 28	b	a	a	a	b	a	b	b	b	a	b	b	a	a	a	b	8
Survey 29	b	a	b	a	b	a	a	b	b	b	a	b	a	b	a	b	5
Survey 30	a	a	a	b	b	a	b	b	b	a	b	b	a	a	a	b	6
Survey 31	a	b	b	a	a	a	c	a	b	a	b	a	a	a	a	b	8
Survey 32	b	b	a	a	b	a	c	b	b	a		b	b	b	a	b	3
Survey 33	a	a	a	a	b	a	c	b	b	a	a	b	a	a	a	b	8
Survey 34	a	a	a	a	b	a	b	b	b	a	a	b	b	b	a	b	6
Survey 35	a	b	a	a	b	a	a	b	b	b	b	b	a	a	b	b	2
Survey 36	b	b	a	c	a	a	b	b	b	a	a	b	a	c	a	b	10
Survey 37	b	a	a	a	b	a	b	b	b	a	a	b	b	c	a	b	5
Survey 38	b	a	a	a	b	a	b	b	b	a	a	b	b	b	a	b	6
Survey 39	b	a	a	a	b	a	c	b	b	a	a	b	a	a	a	b	5
Survey 40	b	a	a	a	a	a	b	b	b	a	a	b	a	c	a	b	8
Survey 41	b	a	a	a	b	b	c	b	b	a	c	b	a	c	a	b	8

Question #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
A	11	28	39	35	4	37	3	1	0	39	31	3	30	12	35	5	
B	29	13	2	2	37	4	15	40	39	2	8	38	11	20	6	36	
C	0	0	0	4	0	0	23	0	2	0	1	0	0	9	0	0	
D	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	

Question # 17	
Range	1-10
Mean	6.83
Median	7
Mode	8

Demographic Data					
Gender	Male	Female			
	9	48			
Years in practice	0-5	6-10	>10		
	43	3	11		
Years in practice with neurology patients	0-5	6-10	>10		
	46	6	5		
Education level	ADN	BSN	MSN	DNP or PhD	Other post graduate degree
	15	38	4		
Do you have a neurology specialty certification	Yes	No			
		57			
Have you had special training in epilepsy or PNES in the past 5 years	Yes	No			
	1	56			

Appendix E. Analyzed Data

Illness Perception Questionnaire-Revised Compared Scores

		Time line (acute / chronic)	Time line (cyclical)	Consequence	Personal control	Treatment control	Illness coherence	Emotional representation	Psychological causal attributions	Nonpsychological causal attributions
	Range	6-30	4-20	6-30	6-30	5-25	5-25	6-30	6-30	12-60
Pre Intervention	Mean	17	14	21	16	14	15	22	22.9	36
	Median	17	16	21	18	14	15	23	23.5	37.5
	Interquartile Range	3	2	2	4	2	4.75	3.5	4.5	7.75
Post Intervention	Mean	16	15	21	17	14	12.7	22	22.9	31
	Median	16	15	22	16	14	12	23	24	30
	Interquartile Range	4	2	3	3.5	3	4.5	3	3.5	3.5
	P value	0.0423	0.8043	0.2842	0.3352	0.4447	0.0005	0.8718	0.9128	0.0035

Most Important Causes of PNES Ranked by Importance, Pre-Intervention

Theme	1st	2nd	3rd	Total
1- Stress worry/ Emotional state	26	22	18	66
2- Personality, Behavior, Attitude, Coping skills	11	6	9	26
3- Drugs/ Alcohol	0	2	5	7
4- Mental illness	2	2	1	5
5- PTSD, accident or injury	2	4	5	11
6- Hereditary	2	1	2	5
7- Poor medical care		4		4
8- other	2	2	2	6

Most Important Causes of PNES Ranked by Importance, Post-Intervention

Theme	1st	2nd	3rd	Total
1- Stress worry/ Emotional state	26	16	18	60
2- Personality, Behavior, Attitude, Coping skills	1	6	3	10
3- Drugs/ Alcohol			1	1
4- Mental illness	1	2	3	6
5- PTSD, accident or injury	14	7	3	24
6- Hereditary	0	0	0	0
7- Poor medical care	0	0	1	0
8- Physiological Causes	1	5	3	3
9- Misdiagnosis	0	0	1	1

Knowledge and Perception Questionnaire (adapted from Shneker and Elliott, 2008)					
	Pre-Intervention		Post-Intervention		*P value
1. The term pseudoseizures is					
Appropriate for use	37	72.5%	11	22.9%	0.0003
Not appropriate for use	14	27.5%	23	62.2%	
2. Pseudoseizures can be diagnosed based on clinical history					
Disagree/somewhat disagree	21	41.2%	23	65.7%	0.0253
Agree/somewhat agree	30	60.8%	12	34.3%	
3. I can differentiate pseudoseizures from epileptic seizures once I witness the event					
Disagree/somewhat disagree	31	60.8%	33	94.3%	0.0005
Agree/somewhat agree	20	39.2%	2	5.7%	
4. Diagnosis of pseudoseizures must always be confirmed by video-EEG monitoring					
Agree	29	56.7%	30	85.7%	0.0181
Disagree- clinical diagnosis can be sufficient	9	17.6%	2	5.7%	
Video EEG is needed only when clinical diagnosis is not clear	13	25.5%	3	8.6%	
5. Inducing the patient's events at bedside by suggestion or doing certain maneuvers confirms that the events are pseudo seizures					
Agree	22	43.1%	2	5.7%	0.0001
Disagree	29	56.9%	33	94.3%	
6. If I can, I try to induce an event					
No	43	84.3%	32	91.4%	0.3318
Yes	8	15.7%	3	8.6%	
7. If prolactin level is not elevated in patient with a spell, this confirms pseudoseizure					
Agree	2	3.9%	3	8.6%	0.4974
Disagree	21	41.2%	11	31.4%	
A patient's prolactin level does not affect my diagnosis	28	54.9%	21	60.0%	
8. Most pseudoseizures are					
Voluntarily induced (patients are fakers)	17	33.3%	0	0%	0.0001
Occur involuntarily	34	66.7%	35	100%	
9. Pseudoseizures occur more commonly in					
Men	7	13.7%	0	0.0%	0.0004
Woman	28	54.9%	33	94.3%	
Occurs equally in men and woman	16	31.4%	2	5.7%	

10. Persons with pseudoseizures can also have epileptic seizures

Agree	44	86.3%	33	94.3%	0.2331
Disagree	7	13.7%	2	5.7%	

11. Patient's with suspected psuedoseizures should first be referred to a:

Neurologist	42	82.4%	26	74.3%	Probably Invalid
Psychiatrist	7	13.7%	8	22.3%	
Psychologist	2	3.9%	1	2.9%	
No referral	0	0.0%	0	0.0%	

12. The best treatment for pseudoseizures is

Medications	10	19.6%	3	8.6%	0.1604
Counseling and therapy	41	80.4%	32	91.4%	

13. Patients with pseudoseizures must have their driving privileges restricted similar to patients with epileptic seizures.

Agree	43	84.3%	26	74.3%	0.1739
Disagree	7	13.7%	9	25.7%	

14. The percentage of patients with pseudoseizures that get better is:

≥25 percent	15	29.4%	11	31.4%	0.6934
26-50 percent	25	49.0%	19	54.3%	
≥51 percent	11	21.6%	5	14.3%	

15. When a patient with pseudoseizures is taking antiepileptic drugs (AEDs) for pseudoseizures:

AEDs should be stopped	28	54.9%	29	82.9%	0.0071
AEDs should be continued	23	45.1%	6	17.1%	

16. Most of my patients when confronted with a diagnosis of pseudoseizures:

Accept the diagnosis	12	23.5%	5	14.2%	0.2705
Do not accept the diagnosis	38	74.5%	30	85.7%	

17. How confident are you in dealing with a patient with pseudoseizures?

Mean	5	6.8	0.000
Median	5	7	
Mode	5	8	

**P-values calculated with Pearson's Chi-Squared test*

Question 17 T-samples tested with 2 Sample T-test at 95% CI

p-value <0.02 considered significant

Appendix F. IRB Letters



**INSTITUTIONAL REVIEW BOARD (IRB)
EXPEDITED APPROVAL**

December 30, 2015

Institutional Review Board
3545 Olentangy River Road, Suite 328
Columbus, Ohio 43214
(614) 566.4431

ohiohealth.com

Amanda J. Cramer, MSN, RN, CNP, CNRN
Grant Medical Center
111 S. Grant Ave.
Columbus, OH 43215

RE: #15-0026

Title: *Nursing Perceptions of Patients with Psychogenic Nonepileptic Spells: Improving Patient Outcomes*

Principal Investigator: Amanda J. Cramer, MSN, RN, CNP, CNRN

Sub-Investigators: John Chovan, PhD, DNP, RN, CNP, CNS; Regina Prusinski, DNP, CPNR-AC

Project Advisor: John Chovan, PhD, DNP, RN, CNP

Dear Ms. Cramer:

I have reviewed, and approved, the above-referenced protocol through the expedited review process. Expedited approval was granted on December 30, 2015 and the full board will be notified at the January 20, 2016 OhioHealth Institutional Review Board (IRB) #2 meeting. Your protocol has been approved for one year for a maximum of 60 subjects.

The following items were reviewed and approved:

- Otterbein University IRB Approval, dated 11/23/15
- Otterbein University IRB Research Summary Sheets
- Petition for Approval of Research Involving Human Subjects, dated 12/14/15
- Protocol, dated 12/21/15
- Budget, dated 11/5/15
- Survey Cover Letter, dated 12/21/15
- Pseudoseizure Questionnaire (2008)
- Illness Perception Questionnaire (IPQ-R) (2002)
- Demographics Survey
- PowerPoint Educational Intervention – Nursing Care for the Patient with Psychogenic Nonepileptic Spells, dated 10/1/15

The IRB approval for this study will expire on December 29, 2016. You will be contacted approximately 3 months before study expiration to provide a yearly Continuing Review Report. As part of our Continuing Review Process, we may randomly review your study to ensure compliance with regulations.

A FAITH-BASED, NOT-FOR-PROFIT HEALTHCARE SYSTEM

RIVERSIDE METHODIST HOSPITAL + GRANT MEDICAL CENTER + DOCTORS HOSPITAL + GRADY MEMORIAL HOSPITAL
DUBLIN METHODIST HOSPITAL + HARDIN MEMORIAL HOSPITAL + MARION GENERAL HOSPITAL + REHABILITATION HOSPITAL
O'BLENESS HOSPITAL + MEDCENTRAL MANSFIELD HOSPITAL + MEDCENTRAL SHELBY HOSPITAL + WESTERVILLE MEDICAL CAMPUS
HEALTH AND SURGERY CENTERS + PRIMARY AND SPECIALTY CARE + URGENT CARE + WELLNESS + HOSPICE + HOME CARE
28,000 PHYSICIANS, ASSOCIATES & VOLUNTEERS

Amanda J. Cramer, MSN, RN, CNP, CNRN
December 30, 2015
Page 2

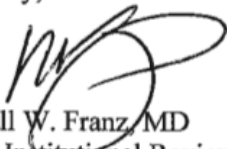
As Principal Investigator of this study, it will be your responsibility to keep all documentation pertaining to the study. Any changes to your study must be reviewed, and approved, by the IRB prior to implementation. The IRB must also be notified of any adverse events that are reported.

All correspondence regarding the study must be identified by the title and assigned project number (#15-0026). Upon completion of the study, you will be required to submit a final written report to the IRB.

The OhioHealth Institutional Review Board is organized and operates according to the Good Clinical Practices, 21 CFR Parts 46, 50 & 56 and applicable laws and regulations.

Thank you for submitting this request to the IRB for review. If you have any questions regarding this matter, please contact the IRB office at (614) 566-4431.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Franz', is written over the printed name of Randall W. Franz.

Randall W. Franz, MD
Chair, Institutional Review Board

RWF/lep

INSTITUTIONAL REVIEW BOARD
RESEARCH INVOLVING HUMAN SUBJECTS
OTTERBEIN UNIVERSITY

☒ Original Review
☐ Continuing Review
☐ Five-Year Review
☐ Amendment

ACTION OF THE INSTITUTIONAL REVIEW BOARD

With regard to the employment of human subjects in the proposed research:

HS # 15/16-08

Chovan & Cramer: Nursing Perceptions of Patients with Psychogenic Nonepileptic ...

THE INSTITUTIONAL REVIEW BOARD HAS TAKEN THE FOLLOWING ACTION:

☒ Approved ☐ Disapproved
☐ Approved with Stipulations* ☐ Waiver of Written Consent Granted
☐ Deferred

*Stipulations stated by the IRB have been met by the investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the college, signed consent forms are to be transferred to the Institutional Review Board for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the IRB, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: 29 Augur 2015

Signed: 
Chairperson

OC HS Form AF

INSTITUTIONAL REVIEW BOARD
RESEARCH INVOLVING HUMAN SUBJECTS
OTTERBEIN UNIVERSITY

☒ Original Review
☐ Continuing Review
☐ Five-Year Review
☐ Amendment

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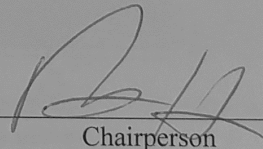
THE INSTITUTIONAL REVIEW BOARD HAS TAKEN THE FOLLOWING ACTION:

☒ Approved ☐ Disapproved
☐ Approved with Stipulations* ☐ Waiver of Written Consent Granted
☐ Deferred

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Date: 23 November 2015

Signed: 
Chairperson

OC HS Form AF

Approval for revisions submitted 21 November 2015.