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A Post Discharge Support Program for Patients Experiencing  
Psychological Non-Epileptic Seizures: A Pilot Project

Lahoma Prather

### Abstract

**Rationale:** There are no accepted standards of care for patients with psychological non-epileptic seizure (PNES) disorder. However the literature regarding PNES identified three common themes including acceptance of the diagnosis; consistent support and follow up; and development of appropriate outcome indicators. This pilot project was designed to address these themes rather than focus on a specific treatment modality.

**Methods:** The pilot project was initiated at the University of Louisville Comprehensive Epilepsy Center (CEC) to evaluate the feasibility of a post-discharge support program for the PNES population. Outcomes identified for measurement included seizure frequency, health care utilization, anti-epileptic medication use and three quality of life indicators.

**Results:** Ten patients were admitted to the program. The five intervention group patients reported declines in seizure frequency, health care utilization and anti-epileptic medication use. Survey return from both the intervention and control groups was minimal precluding statistical analyses. The patients in the intervention group were diverse with regard to psychosocial backgrounds, trauma history, and PNES triggers which allowed the team to view the pilot with regard to patient specific variables leading to the development of a PNES treatment readiness model.

**Conclusion:** Though small in scale, this pilot project adds to the body of knowledge about care of the patient diagnosed with PNES by focusing on identified care themes rather than specific treatment modalities. The Modified RED program will be further developed and evaluated. In addition, the Shafer-Prather PNES treatment readiness model being developed by the team will be evaluated in future work.

## 1. Introduction

Over the last decade healthcare providers and researchers have published more frequently about the nature and cause of psychological non-epileptic seizures (PNES). It is generally agreed that PNES are unconscious, maladaptive coping mechanisms related to past trauma, abuse and/or overwhelming stress (Ali, Jabeen, Arain, Wassef, & Ibrahim, 2011; Baslet, Roiko, & Prenskey, 2010; Myers, Fleming, Lancman, Perrine, & Lancman, 2013; Reuber, Pukrop, Bauer, Derfuss, & Elger, 2004). While the understanding, diagnostic methods, and even name of PNES have evolved over time, guidelines for effective, sustainable treatment continue to be illusive (Dikel, Fennell, & Gilmore, 2003; Lally, Spence, McCusker, Craig, & Morrow, 2010; Reuber, 2007).

Most published treatment studies examine psychiatric interventions as the primary treatment for PNES (Baslet, 2012; Hall-Patch et al., 2010; Mayor, Howlett, Grunewald, & Reuber, 2010). The psychiatric treatments utilized vary and include cognitive behavioral therapy, group psychodynamic therapy, group and individual educational therapy, guided self- help interventions, and eye movement desensitization and reprocessing. Each of these treatments focus on assisting patients in processing past trauma and developing healthy, effective coping mechanisms (Atnas & Lippold, 2013; Goldstein et al., 2010; LaFrance et al., 2009; Oto, 2013; Metin et al., 2013; Quinn, Schofield, & Middleton, 2012; Thompson et al., 2013). These studies show promising areas for future work but have not produced a generally accepted standard of care (Goldstein et al., 2010; LaFrance et al., 2009; Quinn, Schofield, & Middleton, 2012; Sharpe et al., 2011).

While no accepted standards of care have been developed, the literature regarding PNES identified three common themes that guided the development of this pilot project, including acceptance of the diagnosis; consistent support and follow up; and development of appropriate

outcome indicators. This pilot project was designed to address these themes rather than focus on a specific treatment modality.

### **1.1 Understanding and Acceptance of the Diagnosis**

Individuals experiencing PNES frequently do not understand, and may not accept, their new diagnosis (Baxter et al., 2012; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Many patients with PNES have lived for years with the diagnosis of epilepsy. The change in diagnosis from epilepsy to PNES can be challenging, as it is a turn from a definable physical illness with generally accepted treatment plans, to a diagnosis that is not well known and requires delving into psychosocial areas of life that may not be easily penetrated. The journey to healing through processing past trauma, abuse, or overwhelming stress may be more daunting than the original diagnosis of epilepsy (Baxter et al., 2012). Understanding the connection between psychological stressors and the physical manifestations of the seizures is frequently difficult for patients and their families (Baxter et al., 2012; Thompson et al, 2009; Stone, Binzer, & Sharpe, 2004). Effective treatment likely requires ongoing education and reinforcement of treatment plans (Karterud, Knizek, & Nakken, 2010).

### **1.2 Consistent Support and Follow up**

The literature shows that, regardless of the specific psychological treatment modality deemed appropriate for PNES patients, there is need for consistent or increased support for after diagnosis (Mayor et al., 2013; Sharpe et al., 2011). Individuals experiencing PNES often have significant psychiatric co-morbidities including anxiety, depression, posttraumatic stress disorder (PTSD) and suicidal ideation. Most healthcare providers discuss these co-morbidities, as well as PNES, in relation to past trauma or abuse in some manner when delivering the PNES diagnosis to patients (Hall-Patch et al., 2010; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Once this

discussion is held it is incumbent upon the healthcare provider to follow up with patients to validate they have the tools to deal with their issues (Reuber, Mitchell, Howlett, & Elger, 2005). Referrals to appropriate therapists, psychiatrists or other mental health providers are crucial in assuring the patient receives the support needed after diagnosis of PNES (Agrawal, Gaynor, Lomax, & Mula, 2014). However, appropriate referrals to therapists, psychiatrists or other mental health professionals for psychiatric services, along with consistent health provider follow up, can be challenging from both a provider and patient perspective (Grimaldi, Dubuc, Kahane, Bougerol, & Vercuelli, 2010; Lally, Spence, McCusker, Craig, & Morrow, 2010; Scevola et al., 2009). In addition, patients may fail to initiate or may discontinue treatment related to factors including confusion and doubt about the diagnosis, lack of trust in health care providers, and/or lack of resources (Baslet & Prenskey, 2013; Baxter et al., 2011; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). It is important that patients commit to a mutually agreed upon treatment plan and follow up care and that the health care provider commit to providing appropriate levels of support (Karterud, Knizek, & Nakken, 2010).

### **1.3 Development of Appropriate Outcome Indicators**

The goal of treatment with epilepsy is seizure freedom, which is also the traditional metric examined for PNES outcomes (Mayor, et al., 2012; Duncan, Razvi, & Mulhern, 2011; McKenzie, Oto, Russell, Pelosi, & Duncan, 2010; Arain, Hamadani, Islam, & Abou-Khalil, 2007; Reuber, Mitchell, Howlett, & Elger, 2005). However, while seizure frequency is a relevant outcome measure, it is not the sole indicator of healing for PNES patients. Quality of life and ability to function are also becoming expected key indicators of health status for PNES patients (Durrant, Rickards, & Cavanna, 2011; Mayor et al., 2012; Myers, Lancman, Laban-Grant, Matzner, & Lancman, 2012; Van Merade et al., 2004). In addition, decreases in health care

utilization is also used to define successful treatment of individuals experiencing PNES; however, these decreases may not indicate true improvement. Accurate diagnosis may lessen an individual's or their family's views of PNES as medical emergencies. This does not necessarily translate into improvement either in seizure frequency, level of functioning or quality of life (Jirsch, Ahmed, Maximova, & Gross, 2011; McKenzie, Oto, Russell, Pelosi, & Duncan, 2010).

#### **1.4 Pilot Project**

The University of Louisville Hospital Epilepsy Monitoring Unit admits approximately three hundred patients annually for evaluation of intractable seizures. Of this number, 30-40% are definitively diagnosed with PNES during admission. Our experience with PNES patients mirrors the common themes found in the literature. It is not uncommon for patients to make the first report of trauma or abuse at the time of diagnosis which may cause distress and the need for intensive support for the patients and their families. Patients admitted to the unit who receive a PNES diagnosis are often shocked by the radical change in treatment plan and unsure of what their next steps entail. As reported in the literature we have observed that patients find it difficult to make the connection between psychological stressors and the physical manifestations of the seizures (Baxter et al., 2012; Thompson et al, 2009; Stone, Binzer, & Sharpe, 2004).

To address the ongoing care issues of the patients with PNES who present for care at our center, a post-discharge support program was created based on common literature themes and treatment needs of this patient population. The post-discharge support program is a modified version of the Re-engineered Discharge (RED) program created by Boston University Medical Center in conjunction with the Agency for Healthcare Research and Quality [AHRQ], 2013. The Boston University RED program was designed to improve the discharge experience for patients with chronic illnesses, as well as to decrease thirty day readmission rates for these patients. This

was accomplished through patient education and post discharge support primarily through phone calls (AHRQ, 2013). RED was originally designed to address chronic physical health conditions, such as congestive heart failure, and has been shown to be successful in decreasing readmissions rates and improving patient outcomes (Jack et al., 2009). The program consists of twelve components and includes a toolkit on the AHRQ website for healthcare providers interested in initiating the RED program in their facilities (AHRQ, 2013). Modifications to the components and toolkit were made to tailor the program to the specific needs of PNES patients.

This pilot project describes the Modified RED post-discharge support program and examines the feasibility of its utilization for patients with PNES. The pilot project received approval from the institutional review boards of University of Louisville Hospital, University of Louisville, KentuckyOne Health, and Bellarmine University.

## **2. Material and methods:**

### **2.1 Participants/Population**

The target population of the post-discharge support program was adult patients diagnosed with PNES after admission to the University of Louisville Epilepsy Monitoring Unit. Patients included were those over age eighteen admitted to the Epilepsy Monitoring Unit and subsequently diagnosed with PNES during their admission. Both male and female patients were included and there were no exclusions based on ethnicity or other demographic variables. Patients with the co-morbidity of epileptic seizures will be excluded from these guidelines.

The project included an intervention and control group. The intervention group was enrolled in the post-discharge support program while the control group received the standard care of explanation of the diagnosis and suggested referral as needed. Patients were assigned to groups in an alternating manner.



**2.2 Staff**

The project was conducted by the medical director of the epilepsy monitoring unit who presented the diagnosis and approached the patients about participation in the pilot project. In addition, an epilepsy nurse acting as discharge educator/coordinator, initiated and managed the discharge support program, in conjunction with the medical director.

**2.2 Modified RED Program**

The intervention group participated in a modified version of the reengineered discharge program (RED). Modifications to the RED program are outlined in Table 1. The medical director and epilepsy nurse met on an ongoing basis to discuss the program and patient progress.

Table 1  
*Modified RED Program Process for Intervention Group*

| <b>Components of the RED</b><br>(AHRQ, 2013)   | <b>Modifications for PNES Population</b>  |
|--|---|
| 1. Ascertain need for and obtain language assistance.  | <ul style="list-style-type: none"> <li>• No modifications necessary.</li> </ul>   |
| 2. Make appointments for follow-up care (e.g., medical appointments, post discharge tests/labs). | <ul style="list-style-type: none"> <li>• Referrals were made at discharge as necessary including referrals to therapists, psychiatrists, and other mental health care providers.</li> <li>• Education and consults with the epilepsy nurse or medical director about PNES offered to all therapists, psychiatrists, and other mental health care providers working with this population.</li> </ul> |
| 3. Plan for the follow-up of results from tests or labs that are pending at discharge.           | <ul style="list-style-type: none"> <li>• The patient received the seizure monitoring results at the time of diagnosis.</li> <li>• Reinforcement of the diagnosis occurred at each follow up call.</li> </ul>  |
| 4. Organize post discharge outpatient services and medical equipment.                            | <ul style="list-style-type: none"> <li>• Outpatient services needed such as a referral to therapists, psychiatrists, and other mental health providers and community agencies were made at discharge.</li> <li>• Ongoing assessments of service and equipment needs were made during discharge calls which occurred at specified intervals after discharge.</li> </ul>                              |
| 5. Identify the correct medicines and a plan for the patient to obtain them.                     | <ul style="list-style-type: none"> <li>• Medications the patients were to continue taking were included in the patient’s individual discharge booklet.</li> <li>• The medical director had a discussion with each patient to</li> </ul>   |

|   |   |
|---|---|
|   | <p>explain continuing or discontinuing anti-epileptic medications.</p> <ul style="list-style-type: none"> <li>• The epilepsy nurse followed up on the patients’ understanding of continuing or discontinuing anti-epileptic medications during each discharge call.</li> </ul>  |
| 6. Reconcile the discharge plan with national guidelines.                                       | <ul style="list-style-type: none"> <li>• There are currently no national guidelines in place; however, the patient was assessed for distress or immediate needs and referred appropriately.</li> </ul>  |
| 7. Teach a written discharge plan the patient can understand.                                   | <ul style="list-style-type: none"> <li>• The discharge plan included in the RED toolkit was modified to address PNES and developed in conjunction with the patient and tailored to the patient’s specific treatment plan.</li> </ul>  |
| 8. Educate the patient about his or her diagnosis and medicines.                                | <ul style="list-style-type: none"> <li>• A PNES patient education workbook was used during the education process. The workbook included space for patients to document their personal experiences, possible triggers, and questions for providers. The epilepsy nurse encouraged the patient to utilize the workbook and document their experiences to gain insight and understanding of their personal story and to record questions for healthcare providers.</li> <li>• The PNES patient education workbook was forwarded to therapists, psychiatrists, and/or other mental health care providers if requested by patient to aide in provider understanding of PNES.</li> <li>• The medical director and epilepsy nurse were available to consult with therapists, psychiatrists, and mental health care providers as needed.</li> </ul> |
| 9. Review with the patient what to do if a problem arises.                                      | <ul style="list-style-type: none"> <li>• Individualized written plans for crisis, emergent situations or seizure occurrence were created with the patient as part of the discharge process.</li> </ul>  |
| 10. Assess the degree of the patient’s understanding of the discharge plan.                     | <ul style="list-style-type: none"> <li>• The patient was asked to verbalize in their own words their understanding of the diagnosis and encouraged to voice concerns and ask questions. This understanding was assessed prior to discharge at all follow up phone calls.</li> </ul>   |
| 11. Expedite transmission of the discharge summary to clinicians accepting care of the patient. | <ul style="list-style-type: none"> <li>• Discharge summaries were forwarded to the referring healthcare provider as well as providers the patient was referred to with the patient’s consent.</li> </ul>  |
| 12. Provide telephone reinforcement of the discharge plan.                                      | <ul style="list-style-type: none"> <li>• The epilepsy nurse made follow up post-discharge calls at 1 day/ 3 days/ 1 week/ 2 weeks/3 weeks/ 4 weeks/ bi-weekly to 6 months and then every month to 1 year.</li> <li>• A modified RED script was utilized for calls. Calls included asking patients for a verbalization of the understanding of</li> </ul>  |

|         |   |
|---------|---|
|         | <p>the diagnosis, medication review, seizure frequency, healthcare utilization, assessment of current condition/needs, confirmation of follow up appointments, identifying barriers to follow up, and plan for seizure occurrence or emergency situations.</p> <ul style="list-style-type: none"> <li>• Assessment of patients’ experience with follow up psychiatric care including therapists, psychiatrists and other mental health care providers was completed during follow up calls to identify potential issues with care.</li> <li>• Extra calls were made as needed based on patient needs/outstanding issues.</li> </ul> |
| 13. N/A | <ul style="list-style-type: none"> <li>• The patient was asked to complete the Quality of Life in Epilepsy Short Form, The Brief Symptom Inventory and the General Self-Efficacy Scale after diagnosis and at 1 month, 3 months, 6 months and 1 year after discharge.</li> </ul>  |

### 2.3 Outcomes Measures

Outcome measures for the project included the traditional metrics of seizure frequency, health care utilization, and anti-epileptic medication use. In addition, quality of life measures were examined as well. Table 2 describes the outcomes measures and instruments.

Table 2  
*Outcomes Measures for PNES Project*

| <b>Outcome Measure</b>   | <b>Instruments Used</b>   | <b>Data Collection Schedule</b>   |
|--|---|---|
| <ul style="list-style-type: none"> <li>• Seizure Frequency</li> <li>• Health Care Utilization</li> <li>• Anti-Epileptic Medications Use</li> </ul> | <p>Patient reports prior to discharge and during follow-up calls</p>  | <ul style="list-style-type: none"> <li>• Prior to diagnosis</li> <li>• 1 day post discharge</li> <li>• 3 days post discharge</li> <li>• Weekly until 4 weeks post discharge</li> <li>• Every 2 weeks from 1-6 months post discharge</li> <li>• Monthly from 6-12 months post discharge</li> </ul> |
| <ul style="list-style-type: none"> <li>• Quality of Life</li> </ul>  | <ul style="list-style-type: none"> <li>• Brief Symptom Inventory</li> <li>• Quality of Life in Epilepsy</li> <li>• General Self Efficacy Scale</li> </ul> | <ul style="list-style-type: none"> <li>• Prior to discharge</li> <li>• 1 month post discharge</li> <li>• 3 months post discharge</li> <li>• 6 months post discharge</li> <li>• 12 months post discharge</li> </ul>  |

## **Measures Used**

### **2.34 Brief Symptom Inventory**

The Brief Symptom Inventory instrument is a fifty-three item Likert-type measure used to assess patients for psychological problems and support care management decisions, as well as to evaluate patient progress during and after treatment. Patients rate the extent to which they have been bothered by specific symptoms in the previous seven days. The reported Cronbach's alpha ranges between .67-.96 with a test-retest reliability range of .68-.91(Prinz et al., 2013).

### **2.35 Quality of Life in Epilepsy Short form (QOLIE-31)**

The QOLIE-31 is the short form of an instrument that evaluates seventeen measures of overall quality of life, emotional well-being, role limitations due to emotional problems, social support, social isolation, energy/fatigue, worry about seizures, medication effects, health discouragement, work/driving/social function, attention/concentrations, language, memory, physical function, pain, role limitations due to physical problems, and health perceptions. The reported Cronbach's alpha is greater than .70 with test-retest reliability greater than .70 (Davies, Gibbons, Fitzpatrick, & Mackintosh, 2009).

### **2.36 General Self-Efficacy Scale**

The General Self-Efficacy Scale instrument is a ten item psychometric measure designed to assess a patient's general sense of perceived self-efficacy with the aim of predicting ability to cope with daily stressors, as well as adaptation after experiencing stressful life events. This scale was used to evaluate patient beliefs about their ability to cope with daily stressors as they work to replace PNES with health coping mechanisms. Reported Cronbach's alpha for this instrument is .95, with a test-retest reliability range of .69-.80 (Nilsson, Hagell, & Iwarsson, 2015).

### **3. Results**

#### **3.1 Baseline Data**

Ten patients were admitted to the pilot project, five into the intervention group and five into the control group. Overall, eight of the ten patients completed surveys prior to discharge with two requesting to return their surveys via mail so they could be discharged expediently, neither of which were returned. In the intervention group, three actively participated in the project and two could not be contacted after one week post-discharge. Of the five control group patients, only one returned surveys one month post discharge in spite of mailed reminders.

#### **3.12 Intervention Group Patients**

All five of the intervention group patients were female and each had been previously diagnosed with epilepsy. Table 3 contains additional demographic information about the group. Intervention group patients were admitted over a six month period. Two of the five were followed up to four months post discharge with one patient newly admitted at the end of the six month time frame and who remains an active participant in the Modified RED program. Each patient participated in an education session using the education workbook, as well as in developing their own personalized discharge plan. The intervention group was given a copy of the education workbook and discharge plan to take home with them at the time of discharge.

All intervention group patients participated in follow up calls at one day, three days, and one week post discharge. Two patients no longer answered their phones or returned messages after one week post discharge but did not formally withdraw from the pilot. Neither had expressed any issues with the program during the last follow up call they participated in. Three intervention group patients participated in ongoing discharge calls as explained in Step 12 of the Modified RED program. Extra calls were made as needed to assist the patients in accessing

resources as well as to provide continued education and support. Both of the patients followed up to four months returned surveys at one month and three months post discharge as outlined in Step 12 of the Modified RED program. The patient who was enrolled at the end of the six month period has participated in follow up calls and has not been asked to complete the follow up surveys at the time of this report.

During the time period the five intervention group patients participated in the follow up calls each of the patients was able to verbalize what PNES are, their personal journey to diagnosis and report how they were doing at the time of the call. None of the five expressed issues with the timing or frequency of the follow up calls and frequently noted they appreciated the support and felt the calls were helpful.

### **3.13 Control Group Patients.**

The control group consisted of two male and three female patients. All five control group patients had been previously diagnosed with epilepsy. While all five verbalized understanding of their expected participation in the pilot, only one of the five control group patients returned surveys after their discharge, even with reminders sent by mail. None of the five control group patients were followed on an outpatient basis by the medical director so there was no contact from the team after discharge with the exception of the mailed reminders. Additional demographic information about the control group patients may be found in Table 3.

Table 3

*Intervention and Control Group Patient Demographics*

| <b>Demographics</b>                        | <b>Intervention<br/>Group (n=5)</b> | <b>Control<br/>Group (n=5)</b> |
|--|-------------------------------------|--------------------------------|
| Age, mean, years (SD)                      | 28.0 (5.66)                         | 48.6 (12.62)                   |
| Gender (% female)                          | 100                                 | 60                             |
| Marital status (% married)                 | 40                                  | 60                             |
| Ethnicity (% Caucasian)                    | 80                                  | 100                            |
| Employment (% employed)                    | 60                                  | 20                             |
| Trauma history (% confirmed)               | 100                                 | 100                            |
| Psychiatric co-morbidities (%)             | 80                                  | 100                            |
| Age at onset of seizures, mean, years (SD) | 24.0 (4.74)                         | 33.8 (14.25)                   |
| Previous diagnosis of epilepsy (%)         | 80                                  | 100                            |
| Previous anti-epileptic medication (%)     | 80                                  | 100                            |
| Time to PNES diagnosis, mean, months (SD)  | 48.6 (74.95)                        | 180.0 (129.52)                 |

### 3.2 Outcome Indicators

#### 3.21 Seizure Frequency

While active in the program all of the intervention group patients reported via phone call a decline in seizure frequency post diagnosis at week one and month four as shown in Table 4.

#### 3.22 Health Care Utilization for PNES

Intervention group patients reported multiple physician consults, ER visits and at least one hospitalization prior to receiving the diagnosis. During the time period they were active in the program (range one week-four months) none of the patients in the intervention group reported accessing care for seizures after discharge as shown in Table 4.

#### 3.23 Anti-Epileptic Medication Use

All but one of the intervention group patients was taking anti-epileptic medications on admission to the epilepsy monitoring unit (range one-three medications). All medications prescribed for seizures were discontinued at discharge for the four intervention group patients taking them and, per patient report, none were restarted during the time period each intervention group patient was active in the program. The control group patients were left on the antiepileptic

medications they had taken prior to diagnosis and advised to discuss discontinuation of these medications with their primary provider after discharge.

Table 4

*Intervention Group Outcomes 1 Week and 4 Months Post Discharge*

|   | <b>Seizure frequency prior to diagnosis</b> | <b>Seizure frequency 1 week &amp; 4 months post discharge</b> | <b>Anti-epileptic drugs use prior to diagnosis</b> | <b>Anti-epileptic drugs use 1 week &amp; 4 months post discharge</b> | <b>Healthcare utilization for seizures prior to diagnosis</b> | <b>Healthcare utilization for seizures 1 week &amp; 4 months post discharge</b> | <b>Number of calls while active in program</b> |
|---|---|---|--|--|---|---|--|
| 1 | 1-2/week                                    | 0 / 0   | 1 AED  | 0 / 0  | >2 ER / MD visits   | 0 / 0   | 16   |
| 2 | 1-2/month                                   | 0 / Not reported  | 3 AEDs   | 0 / Not reported   | >3 ER / MD visits   | 0 / Not reported  | 3  |
| 3 | 12 daily                                    | 0 / 0   | 3 AEDs   | 0 / 0  | >10 ER / MD visits, hospital stays                            | 0/0   | 39   |
| 4 | 2-8/week                                    | 0 / Not reported  | 1 AED  | 0 / Not reported   | >3 ER / MD visits, 1 hospital stay                            | 0 / Not reported  | 2  |
| 5 | 5-6 daily                                   | 1 per week / Not reported                                     | 0  | 0 / Not reported   | >2 ER / MD visits, 1 hospital stay                            | 0 / Not reported  | 3  |

### 3.24 Surveys

Eight of the ten patients who participated in the pilot project completed the Brief Symptom Inventory, QOLIE-31, and General Self Efficacy Scale prior to discharge. Two of the patients requested to return the surveys after discharge to expedite leaving the hospital but did not return them, even with reminders sent by mail. The patients who completed the surveys had no reported difficulties completing the QOLIE-31 and the General Self Efficacy Scale. Four of



the eight patients reported confusion on how to answer the questions when completing the Brief Symptom Inventory and two stated it took an hour to complete the inventory.

Survey return after discharge was poor. Per section 3.1 we were unable to contact two of the intervention group patients after one week post-discharge and they subsequently did not return the surveys that were sent at one month and three months post-discharge. Of the five intervention group patients, two patients returned surveys after discharge with one patient newly admitted to the program just prior to the discontinuation of enrollment who has not been asked to complete the one month post discharge survey at the time of this report. Of the five control group patients only one returned surveys after discharge. This may have been, in part, because the study did not include a mechanism to promote survey return with the exception of resending the surveys with a reminder note by mail. Control group patients made a verbal commitment to complete and return the surveys; however, the project did not include a plan for formal contact with the team after discharge. Due to the poor return of surveys post discharge it is difficult to ascertain what, if any, results were obtained as statistical comparisons were not feasible and are therefore not reported here.

### **3.3 Understanding and Acceptance of the Diagnosis**

The education workbook, used in Step 8 of the Modified RED program, was used by each patient in the intervention group during preparation for discharge as well as after discharge. Patients made notes about their personal stories that appeared to help them understand the diagnosis. While anecdotal, by telling their stories and writing notes, patients appeared to the epilepsy nurse to accept the diagnosis and changes in treatment plan. In addition, during phone calls all of the intervention group patients mentioned reviewing the workbook after discharge, and asked questions related to the review.

Per patient's requests the workbook was forwarded to the therapists, psychiatrists and other mental health providers that intervention group patients saw post-discharge. After receiving the workbook, one of the therapists requested a consultation with both the epilepsy nurse and medical director to gain a better understanding of the care needs of patients with PNES. Two patients reported that the information in the workbook corresponded with the information they received in their therapy sessions which seemed to reassure them and further promoted acceptance and understanding of the diagnosis.

### **3.4 Consistent Support and Follow up**

The personalized discharge plan, used in Step 7 of the Modified RED program, was utilized for each intervention patient. The discharge plan was developed in conjunction with the patient and included follow up appointments; a list of patient specific trauma resources if applicable; emergency contact information; other contact information the patient might need; information about whether anti-epileptic medications would be continued or discontinued and why; recommendations for self-care; and a patient specific plan for what to do if a patient had a seizure or felt like he or she might be experiencing seizure triggers. By participating in creating the discharge plan the patients were able to verbalize their knowledge of the plan and the next steps following discharge. The personalized discharge plan was included in a binder with the education workbook and the patient was encouraged to take the entire binder to each follow up appointment.

The number of follow up calls per patient varied based on their individual needs. Four of the patients required 3-4 calls in the first week after discharge to answer questions and finalize referrals and then followed the schedule outlined in Step 12 of the Modified RED program. Calls ranged from 5-15 minutes each for these patients. One patient required more intensive post

discharge support and received up to 5 calls a week for the two months post discharge with calls averaging around 15 minutes each. Follow up by the epilepsy nurse for all post-discharge calls included assisting the patient in accessing resources, as well as updates to and discussion with the medical director as needed. Call follow up averaged 20 minutes per call during the first week post discharge and 10 minutes per call for subsequent calls.

The follow up calls gave the patients an opportunity to learn more about their diagnosis, participate in developing their own plan for healing, ascertain appropriate resources and communicate potential barriers to follow up. The calls in and of themselves also provided support to the patients by reinforcing the commitment of the medical director and epilepsy nurse to their ongoing care.

### **3.5 Patient Specific Variables**

Although we did not initially plan to track patient-specific extraneous variables, issues that arose during the initiation and management of the Modified RED program provided insights that led the team to begin to examine the patients' overall life situations on a broader scale when considering appropriate treatment plans. While there were only five patients in the intervention group they were diverse from the perspective of personal resources, abuse and trauma history, family support, and motivation to participate in the program. The post-discharge support program was initiated for each patient in the manner described in the methods section; however, their individual journeys varied based on specific needs and psychosocial issues. The Modified RED program proved to be adaptable to patient specific needs.

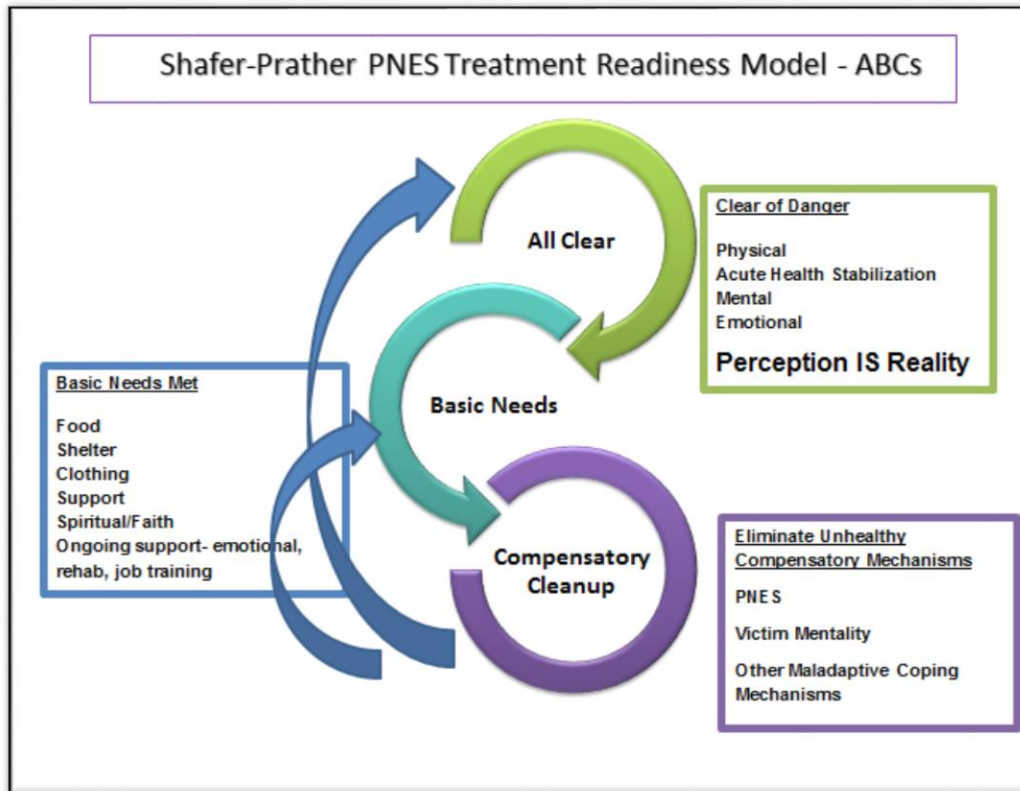
### **3.6 Treatment Readiness**

During implementation of the pilot project, as we considered the individual patient situations, we began to develop the Shafer-Prather PNES treatment readiness model based on

Maslow's Hierarchy of Needs and the Roy Adaptation Model found in Figure 1 (Masters, 2012; Hoffman, 2008). We found that if we applied this model to a patient's individual situation, we could better plan with the patients for consistent, effective follow-up care and support. For example, one intervention patient did not have a safe home and while she desired to see a therapist to work through past trauma as part of her personalized discharge plan, this was not possible until her basic needs were met. Another patient did not have the family support necessary to commit to consistent follow up and this issue had to be resolved prior to patients fully committing to the post-discharge support program. In addition, one of the patients also required support in leaving the initial therapist she was referred to and accessing care from a therapist who was a more comfortable, better therapeutic fit for her. Four of the five control group patients were noted to likely require intensive post discharge support and subsequently did not return the surveys. The single control group patient considered to be in a stable environment was the only patient in the control group to return surveys.

By assessing each of the patients with the Shafer-Prather PNES treatment readiness model on an ongoing basis and understanding that there may be more pressing needs to be addressed before the seizures themselves, the team was better able to offer appropriate support and it appeared these patients became more successful in starting and continuing psychological treatment after immediate issues were addressed.

Figure 1  
*Shafer-Prather Psychological Non-Epileptic Seizures Treatment Readiness Model*



Model adapted from Maslow, Roy (Masters, 2012; Hoffman, 2008)

### 3.7 Discontinuation of Enrollment

The pilot project was originally developed to include a sample of twenty patients; however, several factors prompted the team to stop enrolling the pilot at 10 patients so that modifications could be made before further evaluation was completed. One factor that led to the decision to discontinue enrollment was poor survey return. The lack of surveys returned by the control group was concerning given the objectives of the pilot and the team felt it was necessary to discontinue enrollment to address data collection issues as described in section 4.1.

While the data collection issues were a significant part of the decision to discontinue enrolling at 10 patients, other equally important findings further supported temporary discontinuation of enrollment. The patient specific variables that led the team to begin to develop

the Shafer-Prather PNES treatment readiness model pointed to the need to expand the team to include other disciplines who could act in conjunction with the medical director and epilepsy nurse to strengthen post-discharge support. In addition, the initial positive reactions to the education workbook by patients, and patient request to forward the workbooks to providers, prompted consideration of the development of multiple versions of the workbook as well as the possible addition of an outcomes measure related to the usefulness of the education workbook. The benefits of stopping enrollment will ultimately strengthen the program and improve the likelihood of further feasibility evaluation.

#### **4. Discussion**

The purpose of this pilot project was to initiate the Modified RED post-discharge support program and examine the feasibility of its use for patients with PNES. Several factors identified during the implementation of the pilot project pointed to limitations of the original design of the program. These factors will guide modifications to the program going forward. In spite of the limitations, pilot project strengths were also identified that will be reinforced in revisions to the program as it is developed further.

##### **4.1 Limitations**

By design, this pilot project included a small number of patients and the pilot was discontinued at half the original patient population goal. This small number of patients may not represent the general PNES population. Another limitation of the project was that the intervention group patients were all women and we do not have any data examining how the post-discharge support program benefits men. In our center, 66% of the patients admitted and diagnosed with PNES are women and previous studies have reported that women comprise between 70%-85% of the patient population diagnosed with PNES (Bora et al, 2011; Ahmedani

et al., 2013; Alsaadi & Marquez, 2005). This makes our pilot project relevant to the majority of PNES patients; however, future feasibility studies of the program will need to address the program in regard to men. Our sample also included only those patients who presented to the inpatient epilepsy monitoring unit and were admitted to the medical director of the unit and is not necessarily representative of those patients who are not referred to an epilepsy center or who are admitted to another attending physician.

The most significant limitation of the pilot project was the limited data collection which prevented statistical analyses of the data. The team was unable to contact two of the intervention patients consistently after discharge. In addition, only one of the control subjects returned surveys post discharge making between group comparisons impossible. While this is not completely unexpected given the complicated needs of PNES patients; going forward improvements in management of data collection will include phone contact by the team with the control group a few days prior to surveys being mailed. This contact was not a part of the initial program because the calls may provide a level of support not normally provided after diagnosis of PNES and discharge from the inpatient unit. In addition, greater emphasis will be given during the consent process about the importance of completing the surveys and the potential benefit to PNES patients as whole related to the post-discharge support program.

## **4.2 Strengths**

### **4.21 Modified RED Program**

A key component of the project was the foundation provided by the systematic approach to discharge and follow up provided by the Reengineered Discharge (RED) program. By modifying the RED program and applying it to a population of patients who have not traditionally had a systematic guideline for care; we were able to insert a level of stability that

improved our ability to support patients through their individual journeys. In addition to providing stability, the Modified RED program was found to be adaptable to specific patient needs through the personalized discharge plan and follow up phone calls. The strengths of the Modified RED program point to the feasibility of utilizing it for the PNES population as a whole. Modifications to the pilot will continue to utilize the RED framework.

#### **4.22 Interdisciplinary Team Development**

While the follow up calls were shown to be a valuable component of the modified RED program, there was concern about the amount of time needed to complete the calls and address the support needs of the intervention patients. This was particularly true for the patient who required intensive support in the months after discharge. As a result of the support needs identified in the calls, the medical director and epilepsy nurse were frequently required to reach out to other disciplines on behalf of the patients which added to the time dedicated to follow up. As the program is implemented for more patients it will be necessary to identify ways to maintain the level of support provided to the patients while minimizing the time spent by the medical director and epilepsy nurse in assisting the patients in addressing support and resource needs.

To address identified ongoing support and resource needs, further development of the program will include development of a dedicated interdisciplinary team to participate with the medical director and epilepsy nurse in the support program. The team is in discussion with the University of Louisville School of Social Work to utilize social work students in practicum experiences to assist in implementation of the post-discharge support program and development of a dedicated interdisciplinary team including possible partnerships with community agencies and other health care providers to increase resources for patients.



#### **4.23 PNES Education Workbook**

It became quickly apparent that the education workbook would be an important part of the support program. The workbook was shown to be useful not only as an educational tool but also in providing opportunity for the patients to reflect on their personal experiences and document thoughts and questions on the workbook's journal pages. The education workbook served as a core component of the Modified RED program and has potential to be utilized not only by the medical director, epilepsy nurse and patients but by therapists, psychiatrists and other health care providers as an aide in increasing understanding of PNES. Specific versions of the education workbook will also be developed specific to providers, patients' family and friends, and the community.

#### **4.24 Identified Literature Themes**

The Modified RED post-discharge support program addressed two of the three themes identified in the literature well, while the lack of data collection prevented evaluation of the third theme. The components of the program enhanced the patients' understanding and acceptance of the diagnosis through education, self-reflection and ongoing reinforcement. Consistent follow up and support were addressed through personalized discharge planning as well as the follow up calls that served many purposes including assistance in accessing resources, identifying and eliminating issues, and overall support of the patients. The third theme in the literature, developing appropriate outcomes measures, will be addressed in modifications to the program to improve data collection prior to the further evaluation of the program.

### **5. Conclusions**

While there were only five patients enrolled in the intervention group these patients came from varied psychosocial backgrounds and each had a different source of trauma and triggers of

PNES. This allowed the team to view the pilot through the perspective of each patient's situation. The framework and adaptability of the Modified RED program provided an opportunity for the team to gain knowledge about each patient's situation from a broader perspective leading to them to begin to develop the Shafer-Prather PNES treatment readiness model. This model may explain lack of consistent success in previous treatment studies and will be developed and evaluated in future work.

Though small in scale, this pilot project adds to the body of knowledge about care of the patient diagnosed with PNES by focusing on identified care themes rather than specific treatment modalities. The RED program, which has been traditionally utilized for chronic physical illness, inserts a level of stability in the traditionally turbulent treatment journey of the patient with PNES. By adhering to the steps in the program while adapting it to meet the individual needs of the patients we were able to partner with the patient to formulate a plan that the patient was comfortable with and able to commit to. After the noted limitations are addressed the program will be evaluated on a larger scale in future work at the CEC.

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