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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Department of Counseling and Family Sciences

Program Evaluation of the MEND Program In Its Application of Working with Adult
PNES Patients

by

Ashley Park

A Project submitted in partial satisfaction of
the requirements for the degree
Doctor of Marital and Family Therapy

June 2022

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Marital and Family Therapy

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ACKNOWLEDGMENTS

From the deepest of my heart, I would like to thank everyone who has been on this journey with me. I have been so honored to do this with the belief that everyone has provided me.

I would like to first thank my chairperson, Dr. Brian Distelberg. You have tirelessly poured into my process for the past two years. I am extremely grateful for your efforts to be the best mentor to me. Throughout this journey, you have consistently been available to me and have spent so much of your time helping me. It truly could not have been done without your efforts. For that, I am forever grateful.

Dr. Daniel Tapanes, you are truly the best supervisor. I have learned so much from you and your guidance and support towards me has been immense. Thank you for presenting this science in such a way that I would be inspired to pursue a doctorate degree. I have valued your contributions toward my work and my overall shaping journey. Dr. Zephon Lister, your efforts have helped me tremendously. Thank you for your wisdom, advice, and direction in this process throughout my Master's and Doctoral program journey.

To my mom and dad. You have worked your entire lives to give me a chance to pursue my dreams. I can never thank you enough. I will always be grateful for your unconditional support and cheerleading me on when I couldn't always see the finish line. I share this major accomplishment with you. I hope I continue to make you proud.

To Christian. You have shown me unbelievable amounts of grace and support throughout this journey. You, out of everyone knows exactly what I have endured these past few years. Through that, you have encouraged me, uplifted me, and supported me

every step of the way. I truly could not have done this without you. Thank you for being the best support I could ever ask for.

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ABBREVIATIONS

PNES	Psychogenic Non Epileptic Seizures
MEND	Mastering Each New Direction
WHOQL	World Health Organization Quality of Life
ED	Emergency Department
MEDS	Medications

ABSTRACT OF THE DOCTORAL PROJECT

Program Evaluation of the MEND Program in its Application of Working with Adult

PNES Patients

by

Ashley Park

Doctor of Marital and Family Therapy,
Department of Counseling and Family Sciences
Loma Linda University, June 2022
Dr. Brian Distelberg, Chairperson

This study is a program evaluation of a family systems program, MEND and its application of working with patients who have Psychogenic Non Epileptic Seizures, otherwise known as PNES. This study evaluates PNES patients who have completed MEND focusing and comparing outcome measures like health related quality of life (HRQL), emergency room visits, and medications with PNES patients who have not done MEND. Results suggest that MEND improved PNES symptoms and overall HRQL.

CHAPTER ONE

EXECUTIVE SUMMARY AND PROJECT PURPOSE

Introduction

Living with a chronic illness can be detrimental and feel like an insurmountable challenge. The journey that one may have to face can be arduous, isolating, and demoralizing while trying to navigate ways to cope and bring back a sense of normalcy to one's life. The stress of living with a chronic illness can affect an individual's physical and emotional health in many ways. While a vast amount of chronic illnesses are understood and routinely researched, there remain various illnesses that are not as well versed within the overall community. The lack of research and understanding of certain illnesses negatively impacts not just the medical community but also affects availability of behavioral health resources for PNES patients.

Prevalence of Chronic Illness in Adults

A chronic illness is defined as “a physical or mental health condition that lasts more than one year and causes functional restrictions or requires ongoing monitoring or treatment” (Raghupathi, 2018). In the United States, six in ten adults have at least one chronic illness with four in ten adults having two or more chronic illnesses (CDC, 2021). This is an extremely high prevalence rate and alarming statistic, as chronic illnesses remain the leading causes of death and disability (CDC, 2021). In addition to this, health care costs are at an all time high with \$3.8 trillion annually going toward treating chronic illnesses. Raghupathi (2018) discusses that this is predominantly because of the inability

to effectively manage chronic illnesses in the United States.

A few key elements, such as; identifying those who are at risk, increasing access to data for a population of patients, and coaching patients to make healthier choices and decisions can play a significant role in increasing success outcomes (Raghupathi, 2018). In addition to this, it is important to note that mental health is an aspect of national healthcare that can directly influence chronic illnesses (Raghupathi, 2018).

Psychogenic Non Epileptic Seizures (PNES)

Despite somatic symptom disorders existing in every discipline in medicine, Psychogenic Non Epileptic Seizures (PNES) patients remain the largest subgroup of functional neurologic disorders (Dworetzky, 2015). To date, PNES patients are “responsible for a big burden of healthcare expenses, estimated at approximately \$900 million annually” (Dworetzky, 2015). While there has been some promising shifts in treatment approaches for PNES patients, health outcomes remain quite poor and care continues to be problematic.

The small but growing literature on patients with PNES has shown the correlation of a PNES diagnosis on health related quality of life (Wardrope et al., 2019). There are many challenges with those diagnosed with PNES (Pretorius and Sparrow, 2015). Such as how PNES can create a debilitating effect, how it impacts mood and self-worth, how it overlaps with a trauma history or attachment issues from childhood. Overall, there continues to be a lack of understanding in how the diagnosis of PNES can pose a considerable challenge for patients (Rawlings et al., 2017).

CONTRIBUTING FACTORS

Psychological Factors

Stress

Stress is defined as a process where environmental demands burden an individual's adaptive capacity (Salleh, 2008). Ongoing stress can result in psychological pressures in addition to biological changes that creates further vulnerability for developing an illness. While not all stress creates a negative impact, chronic stress has a significant influence on the immune system. Stress ultimately becomes harmful when "it exceeds our ability to cope, fatigues body systems and causes behavioral or physical problems" (Salleh, 2008). Harmful stress can distress the body, as well as condition individuals to overreaction, confusion, anxiety, and create higher susceptibility to other illnesses.

Harmful levels of stress can be severe and chronic stress can lead to PNES (Pretorius and Sparrow, 2015). According to Pretorius and Sparrow (2015), those with PNES also had higher amounts of stressful events throughout their lifetime. Acute or situational stressors can overwhelm a patient's coping abilities, resulting in developing seizures or ongoing seizure activity. In fact, Tojek et al. (2000) further strengthens this argument suggesting that PNES occurs as a response to increased stress from childhood to adulthood. Participants from Rawlings et al. (2017)'s study indicated that stress was a perpetuating factor of their PNES. Specifically, everyday stress and ongoing seizure activity has been linked. Ultimately, targeting maladaptive stress patterns in the family

can help improve an individual's adaptabilities in the midst of chronic illness (Distelberg et al., 2014).

Depression

Although the primary concern for PNES patients and treatment modalities is reduction of PNES seizure activity, there are secondary complications that often come up with PNES. According to the National Institute of Mental Health (NIH), individuals with chronic conditions and illnesses are at a higher risk of developing depression. The relationship between depression and chronic illness can be bidirectional, as the onset of depression can lead to a chronic illness and likewise, an onset of chronic illness can lead to depression. Individuals who are struggling with their mental health may experience challenges when adapting to their medical conditions or participating in the improvement of their ongoing care. This is relevant for PNES patients. Unlike patients with epilepsy, PNES patients tend to manifest more than solely physical symptoms (Popkirov et al., 2020). While exact rates vary, a recent meta-analysis discovered that over 40% of PNES patients presented with clinical levels of depression and anxiety (Popkirov et al., 2020). Though a specific stressor does not necessarily precipitate seizure activity, reducing levels of depression can help improve health related quality of life in PNES patients.

Trauma

Arnold and Privitera (1996) suggests that the experience of trauma can increase likelihood of the development of PNES seizures. PNES patients with trauma or chronic PTSD, especially those who have dissociative symptoms, can trigger or initiate seizure

activity from flashbacks and recollections (Alsaadi and Marquez, 2005). It was found that PNES patients had higher prevalence of trauma, specifically for those who had strong dissociations and comorbidities (Popkirov et al., 2020). Green et al. (2017) indicated a similar trajectory, stating that PNES patients reported higher levels of trauma and neglect. Many research articles have additionally pointed to a strong correlation between PNES and trauma from sexual and physical abuse as a child. All this to say, it is not uncommon to see a history of abuse present in PNES patients, and the stressors associated with the trauma history may cause or at least perpetuate the PNES symptomology.

Interpersonal Factors

Familial Dysfunction

Seizure disorders like PNES impact far more than the individual (Wardrope et al., 2019). Family dysfunction has been identified as a predisposing factor for the development and ongoing illness progression for PNES (Green et al., 2017). Patients who have poor interpersonal skills or family background that didn't support emotional expression can result in precipitating PNES seizures. In fact, Green et al. (2017) discovered higher levels of stress and dysfunction in PNES families compared to epilepsy families. This is specifically shown in areas of affective involvement, communication, and general functioning. PNES seizures can additionally function to ameliorate interpersonal crises or threatening situations, especially when the individual is unable to identify and effectively express strong emotions (Alsaadi and Marquez, 2005).

Specifically, PNES can function as a means of masking familial conflicts through distress aversion, behavioral avoidance, and repression (Green et al., 2017).

While relationship quality remains to be quite novel in PNES research (Green et al., 2017), there is strong support in existing literature that families of PNES patients are less cohesive, adaptable, and supportive that relates to poor health related quality of life in PNES patients.

Attachment

Attachment has been linked to various health outcomes and behaviors. Individuals who present with insecure attachments have been seen to show more depressive symptoms and ongoing health issues (Meredith and Strong, 2019). Feeney (2001) discusses the implications of attachment styles for patterns of health and illness, specifically describing the substantial evidence of health outcomes to relationship quality and attachment from childhood. Individuals with secure attachment were shown to have health benefits. Contrastingly, those with insecure attachment from childhood were linked to report more physical health symptoms and also have higher levels of negative emotionality. Ultimately, the quality of parent-child relationships from childhood played a significant role in predicting health outcomes as an adult (Feeney, 2001).

Green et al. (2017) discusses that PNES patients have been discovered to have more insecure attachments with their primary caregivers. He and his colleagues further argued that PNES patients with insecure attachments were also found with increased medically unexplained symptomology.

Health Related Quality of Life

The Centers of Disease Control and Prevention describes Health Related Quality of Life (HRQOL) as an individual's perceived physical and mental health over time. HRQOL is important to define in the context of chronic illness to consider the individual's well being and to best increase efforts to individualize and incorporate appropriate quality care.

Decreased health related quality of life is common for patients with PNES. Numerous factors contribute to poorer quality of life in PNES patients. Family functioning has been deemed to be significant in contributing to decreased HRQOL of PNES patients (LaFrance et al., 2013), along with other factors like poor mental health, trauma, misdiagnosis, and more.

Outline of MEND

The Mastering Each New Direction (MEND) program is a biopsychosocial program that integrates an ecological, family systems, and bio-behavioral stress response conceptual framework to serve a population of patients with chronic illnesses. The MEND program is a family systems-based model that specializes in working with a broad range of pediatric and adult chronic illness patients. Some of the chronic illnesses the MEND program works with includes, but are not limited to, Type I and Type II Diabetes, Chronic Kidney Disease, Digestion Illnesses, PNES, various cancers, and more. The MEND program treats a vast number of patients with chronic illnesses that are accompanied with anxiety, body image, treatment compliance, depression, grief and loss, self-esteem, and familial conflict or issues. According to Tapanes (2012), MEND is an

intensive outpatient program that uses a “multiphase program [...] to promote the healthiest biopsychosocial outcomes for children and adolescents who experience a chronic illness.”

The MEND program works with patients and their family systems to improve functioning across all ecological levels. The family system is the key integration of a patient’s treatment to engage the system in a parallel process for an individual patient to achieve optimal health and second order change beyond the program. In order to maintain treatment adherence and improve disease-specific outcomes, the MEND program treats patients over the course of an average of 21 group therapy sessions (three sessions a week for 7 weeks). Group therapy is powerful for a patient’s treatment process, as individual patients are with other patients who also have chronic illnesses. In addition to this, the MEND program integrates individual and family therapy sessions weekly as well as parent psychoeducation. When a patient concludes treatment at the MEND program, he or she has the opportunity to continue the change process by attending weekly support groups for accountability in health. Having the family system be an integral process of a patient’s journey promotes long term and sustainable change for both the patient and their family system.

Ultimately, the MEND program aims to teach “both children and adults how to build resiliency in the face of chronic illness” (Loma Linda University Health, n.d.). The MEND program has helped chronic illness patients and family systems to create new meanings while adapting to both internal and external stress responses, which have positively contributed to the impact of overall health outcomes and the entirety of the healing process.

Project Purpose

The primary purpose of this project is to add to the current existing behavioral health treatment paradigms for PNES patients by introducing an additional psychosocial intervention, MEND, on its application of working with adult PNES patients. As the MEND program is a family systems based process, this evaluation will aim to show that family systems therapy is a necessary intervention to further increase health related quality of life in PNES patients.

Existing literature has shown that attachment styles, chronic stress, trauma, and impact of familial factors and dysfunction can increase the overall disease process and influence health related quality of life in PNES patients. Evaluating a program like MEND, which emphasizes biopsychosocial health from a family systems lens while addressing stress at numerous ecological levels, can further emphasize the need for treating patients from a family systems framework in behavioral health.

In addition to this, this project will aim to further the research and understanding on this patient population specifically within illness progression and increasing viable treatment options in behavioral health, as existing treatment modalities for PNES patients continue to remain limited.

Rationale

Successful psychotherapy treatment options for PNES patients continue to remain unclear (Huff and Murr, 2021). One finding from research does indicate that anti-epileptic drugs and anticonvulsant medications are actually not beneficial in the treatment of PNES (Huff and Murr, 2021). While treatment of PNES remains controversial (Kamil

et al., 2019), psychological interventions continue to be considered the most viable form of treatment for treating PNES. However, even with mental health providers being fairly accessible, follow up, adherence to psychotherapy, and treatment outcomes remain quite poor (Dworetzky, 2016). To date, there are limited therapeutic modalities that have demonstrated a history of effectively treating patients with PNES, let alone shown successful outcomes.

Additionally, PNES patients present with higher levels of family dysfunction and family dysfunction has been correlated to poorer health outcomes and health related quality of life (LaFrance et al., 2013). Despite existing literature on childhood trauma history, insecure attachment styles, and increased stress in the family system for PNES patients, there remains very limited research and data on effective family therapy psychosocial interventions for PNES patients.

Aims of the Study

The purpose of this study was to evaluate the MEND program in its application of working with patients diagnosed with Psychogenic Non Epileptic Seizures, otherwise known as PNES. There were two primary aims. The first part of aim one was to evaluate pre and post program using the patient's self-reported WHOQL measure. The second part of aim one was to examine (ED) visits and medications pre and post program. Aim two examined MEND participants who completed program and matched pair them from those who did not receive behavioral health treatment from MEND. The match pair patients came from the LLUH list of PNES patients from the EMR. Demographics like age, gender, ethnicity, marital status, and commercial insurance were considered as variables

for matched pairing.

Considerations

It is imperative to consider these questions in the development and progression of this program evaluation. What happens to those patients who have medically “unexplained” symptoms who fall under the category of somatic symptom disorders? Why, if there is literature that points to the ineffectiveness of anti-epileptic medications and anti-convulsants (Jafari et al., 2020) and psychotherapy being the most valid approach to treating patients with PNES (Kamil et al., 2019), are chronic illness conditions like PNES not more openly discussed and researched in behavioral health? Further, why isn’t there an emphasis of family therapy for PNES patients despite the numerous literature that points to the interplay of family dysfunction increasing seizure severity, frequency, and duration (LaFrance et al., 2013)? Nevertheless, no research to date has focused on the impact of a family systems based program like the MEND program on the improvement of biopsychosocial health for PNES patients. These are a few questions that will be addressed throughout this project.

Outline of Dissertation

The outline of this dissertation and thesis will be as followed. The first chapter is an introduction to what this study aims to accomplish, the rationale of this program evaluation, and the need of this study in a larger research context. The second chapter will be the literature review, outlining existing treatment paradigms that have successfully worked with adult PNES patients. The third chapter will focus on the

conceptual framework of this project, particularly examining attachment theory and the MEND model. The fourth chapter will be the methodology section of how this project will be designed and executed to further meet the aims of this study. The fifth chapter will discuss the project's outcome. And chapter six will provide a summary of the project outcomes along with a discussion of study and relevance of project to the field of Marriage and Family Therapy.

CHAPTER TWO

LITERATURE REVIEW

Psychogenic Non Epileptic Seizures

Psychogenic non epileptic seizures or PNES, differs from epilepsy though they mirror similar symptomology to epileptic seizures. Unlike epilepsy, PNES is not caused by abnormal brain electrical activity. According to Boesten et al. (2019), PNES can appear like epileptic seizures, though the two greatly differ. Because PNES is not the same diagnosis as epilepsy, patients with a PNES diagnosis may respond differently to treatment. Lesser (2003) states that while PNES may outwardly resemble a diagnosis like epilepsy, non-epileptic seizures are caused purely by emotional distress, with a root of psychological cause. Therefore, therapeutic intervention is essential for patients specifically with a PNES diagnosis.

While there are many forms of therapy like Cognitive Behavioral Therapy (Kamil et al., 2019), Prolonged Exposure Psychotherapy (Myers et al., 2017), and Mindfulness Based Psychotherapy (Baslet et al., 2020) that have a demonstrated history of working with patients with PNES, there continues to remain a gap in therapy regarding the efficacy of successfully reducing seizure activity in PNES patients utilizing a family systems therapy approach. While there has been some value of reducing seizure activity for PNES patients using these therapeutic modalities, there remains a lack of treatment for successful long term reduction in PNES seizures (Smith, 2014). In fact, Reuber et al. (2012) found that nearly 71% of PNES patients continued to have seizures 4 years after being diagnosed and treated. LaFrance et al. (2013) also discussed that many PNES

patients did not experience sustained improvement of their seizures over time.

Despite ongoing literature and research that highlights common encounters of PNES patients with correlation to stress in the family system (Kramska et al., 2020), lack of understanding this diagnosis from a family systems lens can result in ongoing treatment failures. As most of the existing mentioned therapeutic interventions are individually based, the systemic component in integrating the family system can be a critical addition to treatment. Ultimately, the integration of the family system in therapy could bridge this gap in literature.

Examination of the Problem

Nature of Condition

PNES, otherwise known as dissociative seizures, are altered subjective experiences and involuntary movements that decrease self-control (Popkirov et al., 2020). PNES is characterized by “episodes of movement, sensation, or behaviors that are similar to epileptic seizures but do not have a neurologic origin” (Alsaadi and Marquez, 2005). Instead, PNES is a somatic manifestation of psychological distress. Pseudoseizures are described as paroxysmal changes in behavior, autonomic function, and reduced self-control and consciousness. PNES can result in motor, sensory, cognitive, and emotional disturbances. PNES seizures are clinically distinct and have a complex neuropsychiatric etiology (Popkirov et al., 2020). While PNES mimics epileptic seizures, it is considered to be a psychiatric illness (Jafari et al., 2020). Additionally, PNES lacks the detection of

seizure activity in an electroencephalographic (EEG), which would be detected for seizure activity in epilepsy patients.

PNES seizures are hypothesized to occur as a result from the activation of a learned mental representation; this idea of a “seizure scaffold” with simultaneous physiological arousal (Popkirov et al., 2020). A “seizure scaffold” can exist from prior illness experiences, illness beliefs, or instinctive automatisms. A “seizure scaffold” is proposed to activate through the body’s perceived threats or conditioned cues. It is additionally created through the failure of the inhibitory systems. Disinhibition can result in dissociative states as well as during rumination or chronic stress (Popkirov et al., 2020). PNES seizures create physiological components of detaching and dissociating and psychosocial parts of escaping threat values that “ultimately leads to the resolution of a state of distress and parasympathetic activation” (Popkirov et al., 2020).

According to Boesten et al. (2019), patients with PNES can report multiple comorbidities alongside the diagnosis. Alsaadi and Marquez (2005) further emphasize how PNES is not attributed to a single etiology but instead, is a result of different causal pathways. Etiologies of this disorder can include depression, anxiety, affective disorders, panic attacks, obsessive-compulsive disorders, and post-traumatic stress disorder (PTSD). Boesten et al. (2019) also discusses that trauma can be a relevant risk factor in developing PNES, resulting in more severe psychopathology. Brown and Reuber (2016) further describe that etiology in PNES patients is a culmination of dualistic psychological and physical factors. For example, how childhood abuse not only affects brain maturation but also with social functioning in adult PNES patients.

PNES has been hypothesized to be more of a psychological process and should be viewed as such, as the failure to diagnose its psychological nature can present as a challenge and lead to delay in psychological intervention (Kamil et al., 2019). Episodes have been attributed to intrinsic emotional problems or internalized conflicts (Lesser, 2003). This can lead to an increase in stress. As elevated seizure activity is associated with higher levels of stress, this should be taken into account. What is important to consider about the nature of this condition is that the majority of PNES patients report that their seizures are beyond their voluntary control and occur under stress or unexpectedly (Brown and Reuber, 2016). As the body's way of expressing distress and trauma, PNES seizures can further be precipitated from overwhelming circumstances (Yeom et al., 2021). When regulatory processes are already inhibited, coupled with self-threatening concepts like shame or trauma, this can be particularly problematic for patients with PNES as this internal emotional stress response can trigger additional PNES seizures (Roberts et al., 2019).

Essentially, patients with PNES present with greater sensitivity in their threat value, emotional avoidance, and resting-state connectivity, which make the body more susceptible to respond to emotional stress with psychogenic seizures (Roberts et al., 2019). Additionally, while psychogenic non epileptic seizures do not have a neurological origin, the episodes of movement and behaviors mimic those of epileptic seizures (Alsaadi, 2005). However, there are various biomarkers that differentiate epileptic seizures from PNES (Jafari et al., 2020). Bakvis et al. (2010) found that patients with PNES possess higher basal hypercortisolism that was positively correlated to histories of trauma and threat vigilance.

PNES patients are common, with over 10% having seizure emergencies and around 30% of patients are in tertiary epilepsy units (Popkirov et al., 2020). Due to similar symptom presentation, it is common for PNES to be distinguished as epilepsy. However, efforts are further needed to improve awareness of PNES among healthcare professionals, as approximately 1 in 5 patients referred to specialty epilepsy centers actually have a PNES diagnosis (Rawlings et al., 2017). PNES is more prevalent in women than men (Brandt and Puente, 2015) and onset occurs in young adulthood.

It is important to note that a PNES diagnosis is complex and can take about 7 years between seizure activity and definite diagnosis (Jafari et al., 2020). Diagnosis of PNES is based on observing and analyzing seizure experiences. It is common for PNES patients to endure many unnecessary tests and procedures to confirm diagnosis, especially when there is no medical explanation for the seizure (Kamil et al., 2019). Proper diagnosis of PNES is further supplemented by carefully excluding alternative explanations of visible manifestations like epilepsy (Popkirov et al., 2020). According to Huff and Murr (2021), PNES is largely about excluding other diagnoses. Alsaadi and Marquez (2005) emphasize that early recognition and appropriately treating nonepileptic seizures can result in better health outcomes.

Risk Factors

Though there are multiple risk factors of developing this condition, there is currently no known organic or physical cause of PNES (Huff and Murr, 2021). Often times, a patient with PNES will present with numerous comorbidities including history of abuse, family stressors or conflict, attention problems, and behavioral issues.

Specifically, trauma remains a critical risk factor of developing a PNES diagnosis. Trauma, whether psychological, physical, sexual, or emotional, can be an important etiological factor leading patients to be more psychologically unwell, ultimately increasing the possibility of a PNES diagnosis. Childhood abuse, trauma, stressors, and psychosocial risk factors can all contribute to the development and maintenance of PNES (Tojek et al., 2020). Specifically, trauma that results in dissociation can increase the risk of developing PNES. When a patient has chronic dissociative symptoms (Alsaadi and Marquez, 2005), the flashbacks, sensory triggers, and recollections can initiate a seizure.

Other studies suggest that having epilepsy can increase the risk of developing PNES (Jafari et al., 2020). Approximately, 10% of PNES patients were also reported to have epilepsy. This has been hypothesized through observing cases of patients through biological mechanisms but also through recount of experiences in epileptic seizure patients (Brandt and Puente, 2015).

Extensiveness of the Problem (Breadth and Depth)

Often times, patients with PNES are misdiagnosed with intractable epilepsy and can be exposed to unnecessary medications and treatments (Nam, 2021). In fact, as of 2016, approximately 20-25% of patients referred to specialist epilepsy centers were misdiagnosed and actually had PNES (Valente et al., 2016). Misdiagnosis is common for patients with PNES as the overall presentation is prominently associated with motor activity or affective components that mirror epilepsy. For a PNES patient, the lack of understanding or differentiating this diagnosis from epilepsy can result in ongoing injury, morbidity, and significant healthcare costs (Smith, 2014). As Alsaadi and Marquez

(2005) emphasize the need for early detection of PNES symptomology to properly administer treatment, misdiagnosis is an extensive issue for PNES patients.

Additionally, when prognosis of PNES is unclear, appropriate interventions are unable to be administered in a timely manner (Huff and Murr, 2021). This is of critical consideration, as “difficulty categorizing internal emotional states and regulating high arousal may lead to ongoing (possibly automatic) overregulation attempts (Roberts et al., 2019). As a result, without adequately confronting emotionally-induced events, whether it be external or internal stressors, can initiate a cascade of neurological processes that trigger ongoing PNES episodes and also increase possibilities of future episodes. Correctly diagnosing PNES takes about 7-10 years (Brandt and Puente, 2015), resulting in expensive, unnecessary treatments that may be sometimes harmful to the patient. Misdiagnosis also severely diminishes quality of life for PNES patients.

In addition to common misdiagnosis and improper treatments, Smith (2014) discusses that almost half of PNES patients who do attain seizure freedom continue to have a host of adverse outcomes including disability, psychiatric disorders, and dissociative tendencies. The extensiveness of this problem ultimately lies in the inability to find long term, effective therapeutic treatment interventions for not only reducing seizure activity but also in improving other aspects of biopsychosocial spiritual health.

Intrapersonal/Interpersonal Processes that Impact PNES

Existing literature indicates that PNES and stress accumulated from relationships at various ecological levels is correlated to PNES frequency, duration, and longevity (Green et al., 2017). In fact, psychopathology levels are elevated for PNES patients who

report higher rates of neglect, trauma, and insecure attachment relationships (Green et al., 2017). An individual's family or relational problems occurring in the system can be an additive stressor to the PNES patient. The communication, conflict, affective involvement, and overall systemic functioning can influence the problem. Disorganized emotional behaviors or insecure attachment can also predispose an individual to dissociate more in adulthood, increasing the prevalence of seizures and maintaining ongoing disease processes (Hingray et al., 2011).

Green et al. (2017) also discusses that PNES patients had greater interpersonal problems resulting in increased anxiety and depression than compared to epilepsy patients. Stressors in the interpersonal environment can have a profound impact on patients with PNES (Brown and Reuber, 2016). Ultimately, the long-term impact of childhood trauma and acute, persistent stress can contribute to the etiologies of PNES (Popkirov et al., 2020). Popkirov et al. (2020) found that PNES patients were characterized with higher levels of insecure attachment from childhood that was played out in current ecological levels. These ecological levels included familial relationships, with mental health clinicians, and within a wider social environment (Popkirov et al., 2020).

Integration of Family Systems Therapy

According to LaFrance and colleagues (2013), family therapy is warranted if family dysfunction is present in PNES patients. LaFrance et al. (2013) suggests that PNES patients often lack commitment and support from their family members, which contributes to depression levels and poorer quality of life. These findings indicate that

targeting family dysfunction in therapy with PNES patients can be a beneficial approach. As family dysfunction can impact an individual's stress levels, and as stress levels are connected to increased seizure activity, integrating family therapy may be a unique behavioral health intervention to treat PNES.

As there is clear indication and evidence of intrapersonal and interpersonal processes that affect development and ongoing disease processes for PNES patients, a family systems therapy approach is imperative when examining behavioral health treatment options. Lesser (2003) discusses that PNES episodes can result from a patient's stressful interactions with others and increase in conflict. Despite ongoing literature pointing to the correlation of interpersonal stress and family dysfunction influencing PNES, there continues to be a severe lack in research that examines this problem from a relational framework. To date, there is no literature on a family systems based program that emphasizes improving dysfunctional relationships from a biopsychosocial lens in treating PNES patients.

This diagnosis clearly affects far more than the individual (La France et al., 2013). The gap in literature continues to be the lack of family system-based programs or models that can effectively work with PNES patients and their families. Taking a family systems approach to treatment can address the isolating and restrictive tendencies of a PNES patient within the context of their environment, ultimately influencing integration into the community (LaFrance et al., 2013).

Systems of Influence

According to Brown and Reuber (2016), 33.2% of patients with PNES reported sexual abuse as a child, indicating that PNES patients were more susceptible to illness when they had past traumas. Systems of influence for continued development or worsening of this problem include emotional abuse and neglect. Specifically, childhood psychological abuse was a significant influence in individuals maintaining PNES seizure activity. Essentially, the intrapersonal processes which were present, before, during and after childhood trauma leads to maintaining PNES symptomologies and illness activity (Zeng et al., 2018).

Zeng et al. (2018) also discusses how the degree of comorbidities of psychopathology can positively correlate with the severity of current PNES symptomology. The family system is a systemic influence in how this illness progression may develop and be maintained. In the end, there is much more to research and study regarding the interdependent role of the larger system in the etiology and perpetuation of PNES symptomology.

While there is limited data on trauma, stress, and systemic influence for PNES patients, there is research on how these three facets are connected. Papero (2017) discusses the link between stress impacting the individual and the family system, which points to the conceptualization of chronic stress and its role in family dysfunction in PNES patients. Specifically, exposure to chronic stress can lead to disruption in emotional regulation and the ability to carry out skills needed to engage in effective interpersonal interactions (Papero, 2017). As there is data showing the relationship of poor emotional expression and increased PNES seizure activity, a hypothesis can be

made that the increase in family dysfunction can result in chronic stress and lack of emotional regulation, which then can impact PNES symptomologies.

Review of Psychosocial Intervention Programs and Outcomes

Overview

Different forms of therapeutic interventions have been utilized to treat patients who struggle with PNES. Some therapeutic interventions that have been used include; psychoeducation, teaching relaxation techniques, eye movement desensitization, identifying and managing seizure triggers, improving emotional regulation, and narrative reconstruction of memories of trauma (Brown and Reuber, 2016). Overall, existing therapeutic interventions in the current literature have had somewhat successful outcomes with PNES patients, showing promise for the role of psychosocial interventions, but these studies are small, pilot in nature, and even in these few studies, the sustainability of the outcomes are relatively weak.

Mindfulness Based Therapy

According to Baslet et al. (2020), “despite advances in the understanding of functional neurological disorders, evidence-based treatments for psychogenic nonepileptic seizures (PNES) remain limited.” As mindfulness-based therapy focuses on being present and aware, it is a form of psychotherapy that works with individuals to better comprehend their thoughts and emotions, as a way to relieve stress. The study conducted by Baslet et al. (2020), documented weekly frequency of PNES as the primary

outcome measure. The intensity of the seizures, duration of seizures, and quality of life were measured as well.

The retention rate of this study was severely low due to various factors. Of the 144 patients with PNES, only 26 patients completed all 12 sessions of the therapeutic treatment. This was a huge limitation to the study, which can further point to the weakness of using mindfulness based therapy for PNES patients as a viable behavioral health treatment approach. In fact, the significantly low retention rate could also indicate that on average patients who attended sessions were not improving and decided to drop out. While the reason for dropping out was unclear due to the lack of follow up data with participants, this is a possibility to consider.

Regardless, PNES patients who completed the mindfulness based treatment reported improvements in reductions in PNES episode frequency, duration, and intensity. Quality of life was also shown to increase in patients after completion of mindfulness based therapy. However, the success rate of this study was alarmingly consistent with other prospective studies of PNES patients, showing the need for more effective behavioral health treatment interventions. Baslet et al. (2020) proposed that “ideal effective therapies for PNES will provide sustained symptomatic and functional benefit after completion of the treatment.” Mindfulness based psychotherapy can be considered a short-term form of therapy to temporarily help reduce intensity and frequency of seizures in PNES patients (Baslet et al., 2020). This behavioral health therapy can also help increase the quality of life in patients with PNES. While this study adequately described the initial benefit of mindfulness based therapy for the PNES patients who did complete

the treatment, long term data for sustaining seizure freedom is important to consider for future studies.

Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) has had a demonstrated effectiveness when treating somatoform disorders, and therefore PNES is a logical extension of CBT. To this end, LaFrance and colleagues (2009) examined the effectiveness of CBT on reducing seizures in PNES patients. As CBT focuses on changing thinking patterns as well as learned patterns of unhealthy behaviors, this form of therapy emphasizes moving forward through developing effective ways of coping. By utilizing these strategies in a collaborative approach, individuals have the opportunities to face their fears rather than avoiding them as well as learning to calm one's mind and body. This could ultimately help in reducing seizure activity in PNES patients, as the change in cognition and thought patterns can benefit the biological processes of stress, resulting in decreased seizures.

A study conducted by La France et al. (2009) examined 21 PNES patients who started a CBT treatment. Of the 21 subjects, 17 patients completed the CBT treatment. By the end of the CBT intervention, 11 patients reported no PNES seizures. La France et al. (2009) additionally discussed how mean scores on scales of depression, anxiety, quality of life, and psychosocial functioning improved through the CBT intervention. Although this study is very small, and clearly a pilot study with a within subject design, it provides some hope that psychosocial interventions may play an important role in mitigating PNES seizure activity.

Another study conducted by Goldstein et al. (2010), examined the effects of CBT on PNES patients by comparing CBT with standard medical care (SMC). This study employed a randomized controlled trial design which compared CBT with SMC. 66 PNES patients were randomly assigned to either receive CBT with SMC or just SMC alone, in a 4 month time span. The primary outcome assessed in this study was seizure frequency at the end of treatment as well as during 6 month after treatment. Results of this study indicated that combining CBT with SMC was a far superior approach to reducing seizure activity compared to SMC alone. During the 6 month follow up, the CBT treatment group was more inclined to experience at least 3 months of seizure freedom post treatment. However, a limitation of this study was a small sample size as well as sample collection (Goldstein et al., 2010). The strengths of utilizing CBT included being time limited, cost effective, and clinician accessible.

Prolonged Exposure Therapy

Prolonged Exposure Therapy (Myers et al., 2017) specifically works with individuals targeting the effects of post-traumatic stress disorder (PTSD). This form of therapy is considered to be effective in treating individuals with PTSD (Myers et al., 2017). Prolonged exposure therapy (PE) utilizes a manualized form of Cognitive Behavioral Therapy (CBT), by reducing cognitive and behavioral avoidance strategies. By doing so, the aim is to significantly lower anxiety that is associated with trauma. Trauma is processed in two specific ways: imaginal and in vivo. As such, prolonged exposure therapy is hypothesized to significantly decrease PTSD and comorbid issues (Myers et al., 2017).

As PNES patients can have a history of childhood trauma, it is logical to hypothesize that PE might be beneficial for PNES patients with a similar trauma history. The study conducted by Myers et al. (2017) used PE therapy to 18 patients who carried a dual diagnosis of PTSD and PNES. Of the 18 subjects, 16 completed the treatment course. By the final PE session, 13 of the 16 participants reported no seizures, with the other 3 reporting a decline in seizure frequency. Mean scores on scales of depression and PTSD symptoms also showed improvement from the start to the final session. Lastly, a longitudinal seizure follow up indicated that 14 of the 16 participants maintained sustainability results from their last PE session.

Myers et al. (2017) study showed that there was a significant impact from PE therapy on seizure activity as well as PTSD and mood symptoms associated with the trauma. This therapeutic approach seemed to be impactful, as 9 of the 14 patients from the seizure follow up, exhibited some long term sustained effects (e.g. 18 months post treatments).

Gap in Literature

Currently, where there is a gap in literature is the lack of family systems-based programs to treat patients with PNES. All of the mentioned treatments and review of existing program literature are heavily focused on individual therapy. As of current available research, mindfulness therapy, cognitive behavioral therapy, and prolonged exposure therapy are all promising ways of treating patients with PNES. However, all literature found thus far for behavioral health with PNES was associated in doing therapy with individual patients and fails to include families. While individual therapy can be

effective in treating a patient's seizure activity, where true second order change occurs is within the family system. Though PNES is an individual diagnosis, a patient struggling with this illness can also be struggling with this diagnosis within other ecological levels.

When there is stress within the family system, this could directly be influencing the chronic seizures to occur or even worsen for a PNES patient. If an individual struggles with relational problems in the home, this adds as a major stressor or can trigger the traumas that an individual endured throughout their life, resulting in an increase in allostatic stress load in one's body. As a result, increased stress leads to an increase in seizure activity. This is truly where the gap in literature is and thus, this project aims to evaluate a treatment program that does involve the family system in the therapeutic process. As trauma can be an indicator to an individual developing a PNES diagnosis or become a comorbidity, working through the trauma within a family systems lens can be more effective for long term change in the individual and the system. More importantly, this can lead to sustainable change by having a PNES patient attain seizure freedom, ultimately increasing the individual's health related quality of life. As second order change occurs at the systems level (Hall, 2013), this integration can lead to long-term benefits of seizure activity.

Additionally, there is an overall lack of research from a behavioral health lens on this patient population. As already existing studies on PNES have shown that psychotherapy can significantly increase a PNES patient's quality of life and decrease seizure activity, this project could benefit the field of marital and family therapy by increasing the understanding of the application of family systems therapy to this population.

Conclusion

In conclusion, as shown through available research and existing literature, there are existing viable treatment options for patients with PNES and comorbid diagnoses like depression, anxiety, PTSD, dissociation, and more. Though treatment options are available for patients with PNES, what is lacking in literature are viable treatment programs that emphasize family systems or the relational component integrated into the therapeutic work.

Filling this gap in research by evaluating how a family systems program like the MEND program, can be very effective in helping an individual attain seizure freedom as well as work through relational problems between the individual and his or her family system. By doing so, the hope would be that the individual has significant reduction in PNES seizures, duration and quantity of seizures be reduced, as well as increase the individual's health related quality of life. As experiencing and living with a chronic illness can be a detrimental, lonely, and isolating experience, by integrating the family system into the individual's therapeutic work, there can be hope for change and new experience, while navigating through this diagnosis.

CHAPTER THREE

CONCEPTUAL FRAMEWORK

Conceptualizing a Research Problem

Introduction

There is a prevalence and need of expanding research on PNES patients, as current literature on effective psychotherapy approaches for PNES patients is lacking (Valente et al., 2017). Specifically, within the field of family systems therapy, there is a lack in literature regarding effectively working with this population of patients (Smith, 2014). Despite finding research that family dysfunction was higher in patients with PNES compared to patients with epilepsy, currently there are only individually based therapeutic modalities that exist in working with PNES patients (La France et al., 2011).

As seizures can be experienced and attributed to psychological causes (Brown and Reuber, 2016), it is imperative to discuss how to work with PNES patients within a therapeutic context. An overwhelming majority of PNES patients report seizures beyond their voluntary control and most of the seizures fall under the diagnostic criteria for conversion disorder in the DSM-IV (Brown and Reuber, 2016). This emphasizes the need for more clinicians to be aware of the complexities of this disorder in better treating PNES patients.

While there are existing modalities like Cognitive Behavioral Therapy (CBT) and Mindfulness Based Therapy, these are both individually based approaches that do not focus on looking at the systems level to ultimately create second order change. While both CBT and Mindfulness Based Therapy are existing therapeutic modalities in PNES

research, there continues to remain minimal evidence of efficacy for these approaches in successfully treating PNES. However, these two treatment modalities do provide promise that integrating behavioral health in treating PNES patients, might yield benefit through more research and literature over time. Though there is existing research and literature on these approaches working with PNES patients, further research for evidenced based treatments specifically integrating a family systems lens remain limited (Smith, 2014)

Additionally, despite finding literature of PNES patients presenting with fearful, anxious/avoidant attachment styles, there remains a significant lack of research on an attachment lens approach when working with PNES patients. Furthermore, Green et al. (2017), highlighted that interventions focusing on relationship and attachment issues may greatly benefit patients with PNES, as anxiety about interpersonal relationships increased levels of depression and also an individual's health related quality of life, which may also impact seizure activity.

Relevant Concepts within Theoretical Framework (MEND & Attachment)

MEND

Ecological

As MEND is a family systems based program, intervention occurs at different ecological levels. These levels include individual, family therapy sessions, peer, and multifamily group sessions, which then allows for intervention at the micro and mesosystem levels (Distelberg et al., 2014). Different ecological levels are utilized to better support the patient and their family system, as stress permeates in multiple areas of

a patient's lived experiences. According to Distelberg et al. (2014), "this program acknowledges the family as an interdependent system and therefore intervenes on individual, family, social, and healthcare system levels." For an adult PNES patient, different ecological levels can be assessed to better support a patient's experience of wholeness.

Interoception

The concept of interoception focuses on a patient's mind-body connection, where the patient will learn how their emotional thought processes can impact overall physical health (Distelberg et al., 2014). Interoception involves looking inward focusing on both emotional processes and psychogenic cues in the body. While a patient can come into MEND disconnected from their physical body due to the feeling that their body has failed them, MEND emphasizes interoception for patients to become in tune with their bodies. By aligning physical and emotional experiences, a MEND patient may begin to feel more connected to self and move into a state of *congruence*. The impact of being in a congruent space can then begin to facilitate change internally, which then allows for the larger mesosystem level to have systemic changes (Distelberg et al., 2014). For a PNES patient who may be very disconnected from their physical bodies due to the presence of nonepileptic seizures, the concept of interoception can be beneficial in connecting their mind and bodies. Additionally, as seizures can be connected to emotional traumas and pain, understanding the importance of physical forms of seizures being connected to the inability to regulate emotionally is critical.

Shifting patterns through shifting meaning

This concept is integral to MEND's theory of change, as the role of language and changing inaccurate illness narratives are critical to a patient's overall treatment process. Language is used throughout the entirety of a patient's treatment, though the use of language shifts depending on where the patient is *phasically* in the model (Distelberg et al., 2014). During the early stages of MEND, the role of language is used to assess the systemic functioning of the family. Language learning is critical in the beginning of the program to better understand the family system's perceived meanings of illness in their lives (Distelberg et al., 2014). Stress and negative disease outcomes could be impacted when a chronic illness plays a power role in a patient's life (Distelberg et al., 2014). Specifically, when the "illness story supports a stress response pattern that has become maladaptive in that it perpetuates a pattern within the family that leads to further stress and decreased treatment regimen adherence" (Distelberg et al., 2014). The benefit of eliciting the inaccurate illness story is to then use the therapeutic space to externalize and deconstruct the illness narratives. By *shifting patterns through shifting meaning*, a PNES patient and their family system can construct new narratives or meanings for the system that does not include illness where the illness meaning becomes one that is external to the patient.

Second Order Change.

Second order change occurs at a systems level, where MEND assumes that solidifying change and assessing for sustainability is critical (Tapanes et al., 2015). While change is initiated throughout multiple areas of treatment, in order for the family system

to not revert back to previous patterns or homeostasis, deepening and building sustainability into the change process is necessary. As most follow up studies have shown that patients with PNES have not attained long-term seizure freedom (Korman et al., 2019), this is one gap in literature that the MEND program aims to fill with integrating the family system throughout the entirety of a patient's treatment. As all literature found thus far has been conceptualizing PNES patients with the lens of individually focused therapeutic modalities, the integration of the system to create second order change can be a critical component for PNES patients to attain long-term seizure freedom.

Attachment Theory

Attachment Injuries

Revisiting attachment injuries implicitly and explicitly can be impactful, as these deep rooted traumas can affect one's ability to maintain intimacy and coping with challenging symptoms (Marmarosh et al., 2013). By reengaging in a process of restructuring implicit relational processes, more insight and emotion can be brought into current relational experiences. This can foster one's capacity for intimacy, addressing under-regulation and over-regulation of emotions, and facilitating genuine interpersonal interactions. For a PNES patient, repairing attachment injuries can restore emotional regulation and can parallel the process of rupture and repair (Marmarosh et al., 2013). The goal for a PNES patient will be to repair attachment injuries from childhood, which will ultimately strengthen one's core sense of self.

Anxious Ambivalent Attachment Style.

An anxious-ambivalent adult has been given inconsistent care and concern from the primary caregiver (Brown et al., 2008). According to Brown et al. (2008), “these mixed messages about care lead to a hyperactive response in attempts to draw the caregiver into closer proximity when faced with threatening situations.” An adult with anxious-ambivalent attachment style can have a history of persistent negligence from their attachment figure or main caregiver. As a result, when an individual feels threat, loss, or separation, one may resort to deactivation to cope (Brown et al., 2008). This can include not being willing to seek help when needed, in the case of a chronic illness patient. The concept of anxious ambivalent attachment style can be expanded to the PNES population as literature emphasizes an overlap between attachment styles affecting functional neurologic symptom severity (Williams et al., 2019).

Secure Base

A secure base is established when the primary caregiver represents a safe haven for the child to then explore the world. Specifically, when a caregiver allows for emotional containment and also soothes during states of distress while encouraging curiosity and exploration (Marmarosh et al., 2013). In the same way, a mental health clinician can provide a secure base for the client by being consistent, reliable, and emotionally available (Brown et al., 2008). A secure base is critical for an individual to explore the world in a safe way. Once a secure base is established between a therapist and an individual, the individual can get a better understanding of past childhood experiences that can shape the current system. By creating a secure base with an individual the way

that their childhood was insufficient from it, the emotional experience of therapy can be broadened. When a patient has an understanding of the experience of a secure base, this can be expanded into other relationships and ecological levels. A secure base for PNES patients can result in fostering a space that recognizes and champions self-soothing and self-regulating abilities, which can ultimately benefit the patient during times of distress.

Examination of Research Topic through Identified Conceptual Lens

This study aims to integrate two conceptual frameworks and theories. Attachment theory and the MEND model of therapy will be utilized to better understand how to work with this population of patients. Specifically, these two theories will be combined in conceptualizing working with this population in order to improve domains of lived experiences for PNES patients. These domains of lived experiences include increasing the health-related quality of life physically, emotionally, spiritually, and socially.

As MEND is a family systems based program that emphasizes systemic thinking and integrating the family system for creating changes in a systems oriented way (Tapanes et al., 2015), treatment will be emphasized on working through dysfunction present in the family system that can be directly affecting a PNES patient and worsening their seizures. By including family systems work through a PNES patient's treatment, the goal would be to improve relational dynamics between members of a family system. While seizures may seem like an individual diagnosis, seizure disorders like PNES can not only impact the individual living with the seizures but also surrounding family and friends (Wardrope et al., 2019). Therefore, while individually based modalities like CBT and Mindfulness Based Therapy can be effective, for sustainable long-term change,

second order change needs to occur, which is change at the systems level. As MEND “is grounded in family system [...] frameworks and assumes a complex, interdependent relationship between disease activity, stress, parent-child relationships, and family system processes” (Distelberg et al., 2014), this is the lens that will be utilized to conceptualize a PNES patient’s treatment case.

In conjunction to the MEND model, attachment theory can be integrated to conceptualize this unique population by better understanding the impact of insecure attachment in childhood experiences based on childhood trauma and poor caregiver relationships that can lead to interpersonal difficulties as an adult, affecting an individual’s present system (Williams et al., 2019). This can then be used to conjecture the impact of an insecure attachment style on an inability to explore emotions appropriately, which can lead to increased seizure activity in PNES patients. A consideration for psychotherapy is understanding how a PNES patient’s attachment style is being presently enacted in their family system through the form of dissociation, inability to maintain self-cohesion and self-regulation, then impacting all domains of lived experiences.

How MEND and attachment theory can be integrated to best serve this population of patients is by focusing on attachment injuries and traumas from childhood that has led to insecure attachment that is systemically shown in relationships in an adult patient’s family system. As MEND will emphasize family systems work, where attachment theory can come in to be beneficial for PNES patients is to focus on healing attachment injuries and moving towards secure attachment by showing the family system how to best show up for the PNES patient. An example of this is family members like a patient’s spouse

becoming the ‘secure base’ for the PNES patient who may have grown up with anxious avoidant or fearful attachment styles by their primary caregiver. Another example would be a child who has anxious avoidant attachment and PNES and teaching their parents how to best show up for their child by fostering secure attachment. As Jalilianhasanpour et al. (2018) has found that insecure attachment is quite common in patients with somatic symptoms disorders like PNES, focusing on reducing family dysfunction through the recognition of emotional responsiveness can lead to relational closeness, increased self-esteem, less dependence and less over-vigilance.

Additionally, functional neurological symptom severity like the increased activity of seizures in a PNES patient has been correlated to attachment injuries and traumatic experiences from childhood (Williams et al., 2019). Therefore, integrating attachment theory and family systems work can be a curative and extremely critical treatment experience for a PNES patient.

Implications of the Theories

Integrating the theoretical lens of attachment theory and MEND in conceptualizing PNES patients can be an effective way to consider PNES patients. However, there are additional implications to consider when using both the MEND model as well as attachment theory.

As this study will emphasize a program evaluation of a family systems-based program, an implication of attachment theory to consider when conceptualizing this work with PNES patients is the lack of specific interventions in how to create a secure base. Though attachment theory emphasizes the need for an individual to have a secure base,

there are no specific interventions that indicate what this would look like within a system. However, attachment theory does imply the need for the therapist to be responsible in creating a secure base for the patient (Brown et al., 2008). This is where the MEND model fills the gaps of attachment theory, as the MEND program is a phasic based program that has specific therapeutic interventions to guide a therapist working with patients. Another implication of attachment theory to keep in mind is that though “early experience often plays a critical role in the developmental dynamic that yields pathology” (Sroufe et al., 1999), there are other contextual environmental processes that may influence the nature of a later experience. In essence, though a lack of secure attachment in childhood can lead to various circumstances, an implication to consider is that PNES is not directly caused by an anxious avoidant attachment.

Other implications to consider under the attachment theory lens is that the definition of attachment has been adapted toward Western middle-class individuals (Brown et al., 2008). While this can be an effective theory in conceptualizing towards Western middle-class individuals, it is important to also consider the implications of attachment throughout other cultures and ethnic groups. While attachment theory can be utilized for PNES patients in middle-class Westernized groups, this theory may not be suitable across every culture and ethnic group (Brown et al., 2008).

An implication of the MEND model to consider when working with PNES patients is that MEND is a family systems based program (Tapanes et al., 2015). As not everyone has family or the system is not always accessible, this is important to keep in mind when working with adult patients. This program may not be suitable for those patients who do not have a system to bring into treatment and can become a potential

limitation. As the MEND model emphasizes second order change that occurs at the systems level, bringing in the family system is a critical component of treatment. Another implication of MEND to consider is the length of time in treatment. As the therapeutic process does take time, money, and energy to complete, this form of treatment may not be for everyone.

Conclusion

As a diagnosis of PNES has an underpinning of psychological origin and is considered to be a conversion disorder, psychotherapy is the most appropriate and valid approach in treating PNES (Smith, 2014). Existing literature of PNES patients continues to lack the inclusion of family systems therapy with limited research on the integration of an attachment lens. Therefore, this study continues to aim to bridge this gap of literature through evaluation of a family systems-based program, the MEND program by also utilizing an integration of attachment theory to refute current treatment paradigms that have not shown long-term effects of attaining seizure freedom.

CHAPTER FOUR

METHODOLOGY

Data was collected from the Electronic Medical Record (EMR) from Loma Linda University Health for all patients with PNES. Data was primarily focused within a 5 year time frame, from 2016-2021. The data collection and management processes was approved by the Loma Linda University Internal Review Board (IRB) prior to data collection. IRB determination request #5210455.

Participants

The current study included 918 PNES patients extracted from the LLUH EMR. 41 of those patients were referred to the MEND program. 32 of the 41 PNES patients referred to the MEND program completed treatment. Therefore, 32 MEND PNES patients were examined and matched paired across the primary list extracted from the EMR.

Summary Statement

This project employed a retrospective design, utilizing data that currently exists of PNES patients in the LLUH Electronic Medical Record (EMR). The primary goal of this study was to evaluate the current PNES population within the LLUH system, the prevalence of engagement in behavioral health services, and specifically the outcomes associated with the MEND model with PNES patients. The project evaluated PNES

patient data for two nested samples: 1) all LLUH patients diagnosed with PNES between 2016 and 2021, and 2) a subsample of these patients who attended the MEND program.

Target Population

The population of this study was adult PNES patients, who currently exist in the LLUH EMR between 2016-2021. The first subsample of this study was the PNES patients who completed the MEND program between that same timeframe. The second subsample of this study was PNES patients from the LLUH list matched paired to the MEND patients.

Sampling Process

The sampling process for this study encompassed going into the Loma Linda University database Electronic Medical Record (EMR) once IRB approval had been achieved. A strict rubric was followed once IRB approval had been granted, where the research team went into each of the approved PNES patient's medical records and worked on documenting key processes, which will be discussed later in this chapter. A longitudinal analysis was then conducted of adult PNES patients who completed at least 10 days of the MEND program compared to those PNES patients who did not receive any behavioral health from MEND.

For aim one of this study, there was two different sampling processes used. Aim one examined MEND only participants of the larger LLUH EMR list between the years of 2016-2021. The first part of aim one examined pre and post WHOQL data of 17 MEND PNES patients who completed the program. The second part of aim one used the

EMR to examine frequency of Emergency Department (ED) visits and medications for 32 MEND PNES patients.

Aim two of this study involved match pairing the MEND only list to the larger LLUH PNES patient list, specifically comparing participants' ED visits and medications. The 32 MEND participants were match paired with non MEND participants on demographic variables like age, ethnicity, marital status, and insurance. This design was done to examine the differences of PNES patients who complete MEND versus patients who did not.

Sampling Frame

The sampling frame was taken from the population of PNES patients from the LLUH EMR. The sampling frame had all patients' information present, with their demographics and other relevant information present. The validity of choosing this approach was that this study focused on what it was designed to measure while also focusing on the intention of this study. As one of this study's aims was to evaluate the application of the MEND program on PNES patients, this approach additionally assessed how well the results corresponded to a reliable measurement.

Inclusion Criteria

Criteria for eligibility included all patients who had been diagnosed with PNES within the time frame of 2016-2021 and were in the LLUH EMR. This study targeted those who solely had PNES as well as some patients who had the presence of both epilepsy and PNES. For the first subsample, this project examined PNES patients who

completed the MEND program. Program completion was considered finishing at least 10 treatment days. The first subsample were required to have both pre and post outcome World Health Quality of Life Brief Measure available for comparison. Those patients who did not complete MEND or who did not have both pre and post data available were still documented in the study but were not considered as part of the subsample for this part of the study.

The second subsample examined PNES patients who completed the MEND program and matched pair PNES patients who did not received treatment from the MEND program within that same time frame. Criteria for eligibility included PNES patients who had these listed demographic variables available in the EMR: age, gender, ethnicity, marital status, and insurance.

Exclusion Criteria

For this study, the exclusion criteria entailed patients who did not have PNES. While the MEND program works with a host of patients with chronic illnesses and comorbid disorders, as the target population was patients with PNES, other graduated MEND program patients who completed the program were excluded. As this study involved patients who have completed the program, at least 10 MEND IOP sessions would have had to be completed in order for the patient to be considered part of the sample for this study. Those who had only done a few treatment days were not included.

Research Focus

The primary research questions of interest in this study focused on “How can the field of systems therapy effectively work with patients with Psychogenic Non Epileptic Seizures through the MEND program using an attachment theory lens?”

As mentioned previously, there were two parts of aim one. The first part of aim one was to evaluate pre and post program using the patient’s self-reported WHOQL measure. The second part of aim one was to examine (ED) visits and medications pre and post program. Two different sampling processes were used for aim one. For the first part of aim one, only 17 of the 41 MEND participants were considered because they had both pre and post WHOQL data available.

Aim two examined the 32 MEND participants who completed program and match pair them from those who did not receive behavioral health treatment from MEND. The match pair patients came from the LLUH list of PNES patients from the EMR. Demographics like age, gender, ethnicity, marital status, and commercial insurance were considered as variables for matched pairing.

Aim One

WHOQL

Aim one evaluated how the MEND program could work with PNES patients, specifically examining if there was a significant increase of health related quality of life in all biopsychosocial domains through the WHOQL from completing MEND. The hypotheses for this aim were:

H1: PNES patients who completed MEND increased in their total WHOQL score from

pre and post MEND.

H2: PNES patients who completed MEND increased in their physical WHOQL score

from pre and post MEND.

H3: PNES patients who completed MEND increased in their environment WHOQL score

from pre and post MEND.

H4: PNES patients who completed MEND increased in their psychological health WHOQL score from pre and post MEND.

H5: PNES patients who completed MEND increased in their spiritual WHOQL score

from pre and post MEND.

H6: PNES patients who completed MEND increased in their overall WHOQL score from

pre and post MEND.

Emergency Department (ED) Visits and Medications

The second part of aim one was to evaluate how the MEND program could work with PNES patients, specifically examining if there was a decrease in both ED visits and medications pre and post program. The hypotheses for this aim were:

H1: PNES patients who completed MEND decreased in ED and urgent care visits pre and post MEND.

H2: PNES patients who completed MEND decreased in total medications pre and post MEND.

H3: PNES patients who completed MEND decreased in psychotropic medications pre and post MEND.

H4: PNES patients who completed MEND decreased in seizure medications pre and post MEND.

H5: PNES patients who completed MEND decreased in sleep medications pre and post MEND.

Aim Two

Medication Titration and Emergency Room Visits

The second aim of this study examined medications and emergency room visits across all PNES patients in the EMR from 2016-2021 for patients who have completed the MEND versus those who have never received behavioral health from MEND. The hypotheses for this aim were:

H7: Those who completed MEND had a decrease in ED visits compared to those who have never received any treatment from the MEND program.

H8: Those who completed MEND decreased in all medications compared to those who have never received any treatment from the MEND program.

Research Design

Type of Design

This study was a retrospective, chart review design with a matched pair control condition. Data was abstracted from 2016-2021. Unlike traditional interventional studies, conducting a retrospective study design utilized existing data and involved a relatively quick and inexpensive approach which was helpful for a future prospective study (Toftagen, 2012). Though control groups are not always common in retrospective studies, this study aimed to include a control group (adult PNES patients who have not completed the MEND program) to further assess if there was an impact of the MEND program on adult PNES patients, particularly examining potential differences between PNES patients who completed the MEND program and PNES patients who did not.

As this study used retrospective data, true random assignment was not feasible. Instead, preexisting patients who have completed the MEND program versus those who have not done MEND were compared to assess for the outcome measures that this study aimed to accomplish. While the groups were not randomly assigned, any systematic differences between them were assumed to be due to the treatment and not on the confounding variables (Thomas, 2020).

Validity and Reliability

The choice of using a quasi-experimental method approach for this study was to have higher external validity than most true experiments, as this study focused on more real-world behavioral health interventions rather than an artificial laboratory setting (Thomas, 2020). Additionally, a quasi-experimental method resulted in higher internal validity than other non-experimental types of research, as there was more control over confounding variables than other studies.

However, when choosing a quasi-experimental method approach and retrospective design study, it was critical to consider additional threats to both internal and external validity. This study could result in lower internal validity than true experiments that employed a randomized controlled trial. In addition to this, the use of retrospective data could be inaccurate or incomplete, which was something to consider as this program evaluation and study progressed.

Justification of the Design

The choice of conducting a retrospective design study was to provide a vehicle for future prospective studies and research by using existing data (Toftagen, 2012). By choosing a retrospective, matched pairs design for my study, tighter control of variables were feasible, which made it easier to notice the cause and effect as well as it being relatively easy to replicate in the future. Additionally, there were lesser participant variables and lower risk of demand characteristics. The primary advantage of using a matched pairs design was to have experimental control and reduce one or more sources of

error variability. Also, it helped to enforce a balance between important participant characteristics that could inadvertently affect the outcomes.

As this study had a very small sample size, choosing a matched pairs design was beneficial. However, with choosing a matched pairs design, one consideration prior was to include the availability of the number of participants to justify this study. Because this study relied on a very specific patient population with a diagnosis of PNES, there was not accessibility to a big sample size. It was also important to note that this was still an experimental design so it did not account for all confounding variables.

CHAPTER FIVE

PROJECT OUTCOME

Sampling

This project involved sampling all PNES patients from the Loma Linda University health database EMR. There was a total of 918 patients diagnosed with PNES between the timeframe of 2016-2021 accessible in the Loma Linda University Health Medical Record (LLEAP). Of these, 41 had been referred to MEND and 32 matched pairs were included in this project sample.

Introduction

As discussed in the methodology chapter, two different sampling processes were used for aim one. For the first part of aim one, only patients with pre and post WHOQL data were included. Of the 918 patients in the EMR, 41 patients were referred to the MEND program. Of the 41, 32 patients had 10 or more IOP sessions, 17 had completed pre and post WHOQL measurements. Of those, one individual did not have pre WHOQL data available but did have post WHOQL data. A mean imputation was used to include this individual's data in the analysis. The remaining 22 patients started MEND but either did not have WHOQL data available, or did not complete enough days of treatment to be included. The second part of aim one focused on the frequency of ED visits and medications pre and post MEND program. In this case, all 32 patients that completed MEND and had retrievable ED visits and medication records in the EMR were included in the analysis.

Aim two examined data between two groups: those who have completed MEND and those who never received treatment from MEND. A matched pair design was utilized to compare ED visits and total medications, psychotropic medications, seizure medications, and sleep medications between the two groups. Demographic variables including age, gender, ethnicity, marital status, insurance coverage were used to match pair the two groups.

Statistical Results

Aim One: WHOQL

A paired samples t-test was run to determine if there was significant difference in WHOQL scores pre and post the MEND program. Table 1 below shows the total and subscale scores of the 17 MEND patients.

Table 1. Pre and post MEND comparison WHOQL.

WHOQL	Pre MEND M(SD)	Post MEND M(SD)	t-value	df	p-value	Cohen's d	n
Total	46.86 (12.56)	80.63 (14.74)	8.23	16	<.001	2.00	17
Physical	41.25 (19.14)	81.93 (16.97)	8.37	16	<.001	2.03	17
Psychological Health	40.88 (17.27)	79.90 (17.32)	7.43	16	<.001	1.80	17
Social Relationships	50.71 (28.87)	72.06 (23.00)	3.24	16	.005	.786	17
Environment	60.35 (13.49)	84.74 (12.35)	6.51	16	<.001	1.58	17
Overall	40.82 (15.30)	84.61 (15.64)	8.92	16	<.001	2.16	17

On average, PNES patients showed significant improvements on all of the WHOQL domains. For example, MEND patients reported low total WHOQL score ($M = 46.82$, $SD = 12.56$) before MEND, which increased significantly after MEND ($M = 80.63$, $SD = 14.78$). This improvement, Mean Difference = 33.77, was statistically significant, $t_{(16)} = 8.23$, $p < .001$. This equates to an effect size of Cohen's $d = 2.00$. PNES patients also reported low physical WHOQL score ($M = 41.25$, $SD = 19.14$) before MEND, which increased significantly after MEND ($M = 81.93$, $SD = 16.97$). This

improvement, Mean Difference = 40.68, was statistically significant, $t_{(16)} = 8.37, p < .001$. PNES patients reported low psychological health WHOQL scores ($M = 40.88, SD = 17.27$) before MEND, which increased significantly after MEND ($M = 79.90, SD = 17.32$). This improvement, Mean Difference = 39.03, was statistically significant, $t_{(16)} = 7.43, p < .001$. PNES patients reported low social relationships WHOQL score ($M = 50.71, SD = 28.87$) before MEND, which increased significantly after MEND ($M = 72.06, SD = 23.00$). This improvement, Mean Difference = 21.35, was statistically significant, $t_{(16)} = 3.24, p = .005$. PNES patients reported low environment WHOQL score ($M = 60.35, SD = 13.49$) before MEND, which increased significantly after MEND ($M = 84.74, SD = 12.35$). This improvement, Mean Difference = 24.40, was statistically significant, $t_{(16)} = 6.51, p < .001$. Lastly, PNES patients reported low overall WHOQL score ($M = 40.82, SD = 15.30$) before MEND, which increased significantly after MEND ($M = 84.61, SD = 15.64$). This improvement, Mean Difference = 43.74, was statistically significant, $t_{(16)} = 8.92, p < .001$. Figure 1 below demonstrates WHOQL outcomes pre and post MEND.

This supports the initial hypothesis that PNES patients who attend the MEND program did in fact increase in the domains of health related quality of life through the WHOQL, and suggests a significant effect.

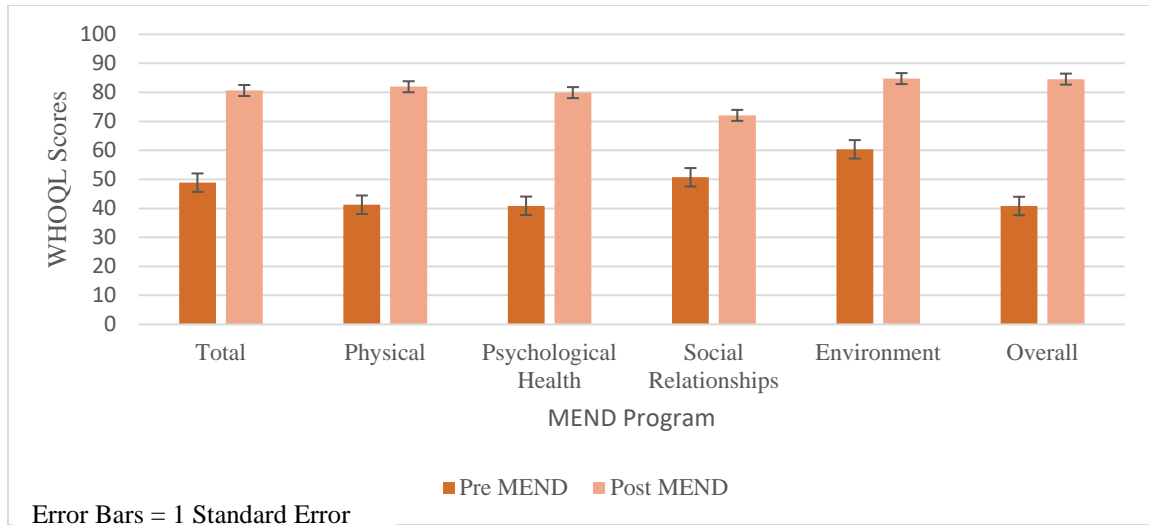


Figure 1. WHOQL outcomes pre and post MEND.

Aim One: Emergency Department (ED) Visits

This step in aim one evaluated the hypothesis that PNES patients who completed the MEND program would have a total decrease in emergency department and urgent care visits after completing MEND. A paired samples t-test was run to determine if there was significant difference between pre and post MEND program ED visits. ED visits were recorded from the patient’s record and the total number of visits, as well as unique PNES related visits were summed to create the dependent variable. Table 2 below shows the total and PNES related ED visits pre and post MEND.

Table 2. Pre and post MEND ED visits.

ED Visits	T1 (Pre)	T2 (Post)	t-value	df	p-value	Cohen’s d	n
Total Visits	5.13 (6.70)	1.50 (2.94)	3.07	31	= .004	0.54	32
PNES Related	1.69 (1.839)	0.22 (1.070)	4.411	31	<.001	0.78	32

Prior to treatment MEND, PNES patients had more ED and urgent care visits ($M = 5.13$, $SD = 6.70$) than after completing the program ($M = 1.50$, $SD = 2.94$). This reduction of, $M = 3.63$, was statistically significant, $t_{(31)} = 3.07$, $p = .004$. All but 6 patients had one or more ED or urgent care visit in the 12 months before starting MEND, while 63% of patients had 5 or more ED and urgent care visits before MEND. Conversely, 12 months post MEND, 69% of patients had 0 ED and urgent care visits.

Furthermore, this analysis considered ED and urgent care visits that were specific to PNES only. On average, 78% of PNES patients had at least one ED visit related to PNES 12 months before MEND. Conversely, 12 months post MEND, 94% of patients who completed MEND had no PNES related ED or urgent care visits post program. This was a statistically significant reduction as patients on average had ($M = 1.69$, $SD = 1.84$) PNES visits before MEND (median 1.0) and, ($M = .22$, $SD = 1.07$) with median of 0.00 PNES visits 12 months post MEND. This reduction of, $M = 1.47$ visits per year post MEND, was statistically significant $t_{(31)} = 4.41$, $p < .001$.

Given this finding, it suggests that PNES patients who attend the MEND program do decrease both the total ED/urgent care visits as well as decrease PNES related visits. Furthermore, the reduction in ED visits achieved a moderate effect size ($d = 0.54$) but an even stronger effect for PNES specific visits ($d = 0.78$). Figure 2 and 3 below demonstrates total ED visits and PNES related ED visits pre and post MEND.

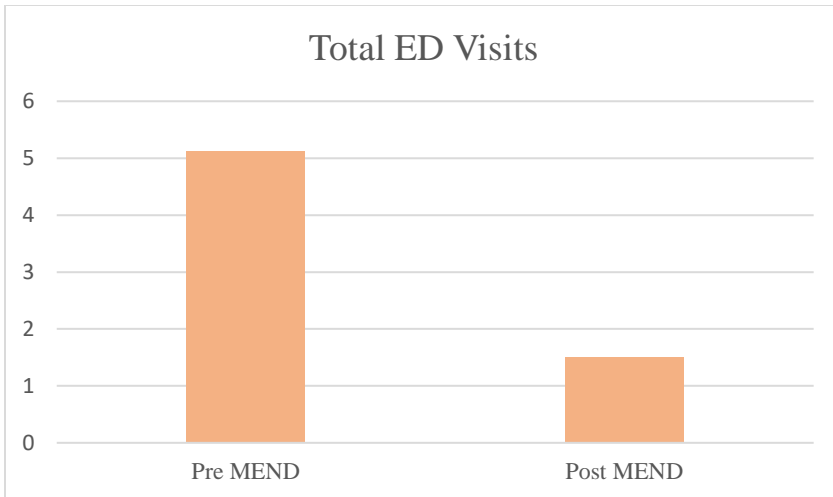


Figure 2. Total ED visits pre and post MEND.

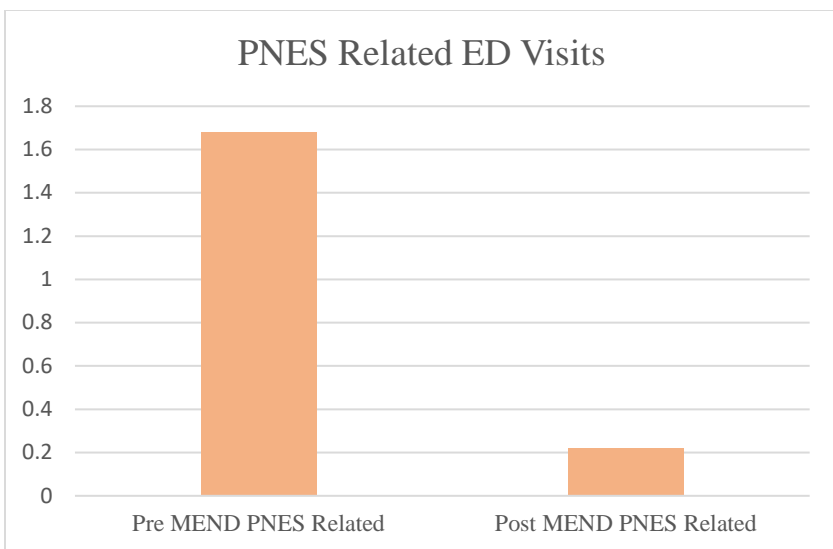


Figure 3. Total PNES related ED visits pre and post MEND.

Aim One: Medications

Aim one also tested whether the MEND program showed a reduction in the number and type of medications patients received. The hypothesis tested was that PNES patients who completed the MEND program would have a decrease in number of total

medications, psychotropic medications, sleep medications, and seizure medications. A paired samples t-test was run to determine if there was significance pre and post MEND program, and the results are reported in Table 3 below.

Table 3. Pre and post MEND medications.

Medications	T1 (Pre)	T2 (Post)	t-value	df	p-value	Cohen's d	n
Total Meds	9.13 (6.12)	8.63 (6.21)	0.768	31	= .448	.136	32
Psychotropic	2.22 (1.66)	1.81 (1.31)	1.32	31	= .196	.234	32
Sleep	0.13 (.336)	0.06 (.246)	1.00	31	= .325	.177	32
Seizure	1.09 (1.17)	0.53 (.803)	3.974	31	< .001	.703	32

Overall, there was a measured reduction in each of the medication domains, but only the reduction in seizure medications resulted in a statistically significant reduction. To this end, prior to treatment at MEND, PNES patients had more total medications ($M = 9.13$, $SD = 6.12$) than after completing the program ($M = 8.63$, $SD = 6.21$ $t_{(31)} = .768$, $p = .448$); although this was not a statistically significant decrease. Similarly, there was a noted reduction for psychotropic medications (pre-MEND $M = 2.22$, $SD = 1.66$ post MEND $M = 1.81$, $SD = 1.31$), which was not significant $t_{(31)} = 1.32$, $p = .196$, but is trending towards significance which might indicate a power limitation. There was a lack of change in sleep medications (Pre MEND $M = 0.13$, $SD = .336$ Post MEND $M = .06$, $SD = .246$) showing no statistical significance, $t_{(31)} = 1.00$, $p = .325$. Conversely, there was a significant reduction in seizure medications. Prior to treatment MEND, 66% of PNES patients had at least one seizure medication ($M = 1.09$, $SD = 1.17$). Post MEND

program, 78% of PNES patients had zero seizure medications ($M = .53, SD = .803$). This improvement, Mean Difference = 0.563, was statistically significant, $t_{(31)} = 3.974, p < .001$, with a relatively strong effect size ($d = 0.70$).

Therefore, the initial hypothesis that PNES patients who attend the MEND program would decrease in medication was partially supported. Total medications, psychotropic medications, sleep medications did not reduce significantly, but seizure medications showed a significant and clinically meaningful reduction after completing MEND. Figure 4 below demonstrates these results further.

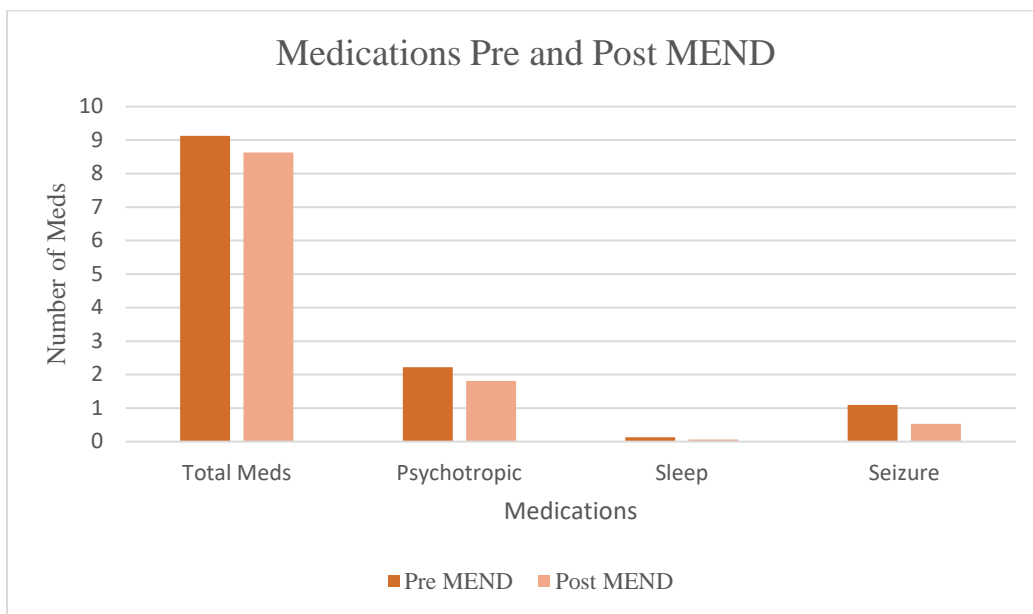


Figure 4. Pre and post MEND medications.

Aim Two - Matched Pair to MEND Group

Independent statistical tests were run to assure that the matched pair group was similar to the MEND group for the start of treatment. Based on the data shown, the MEND group and the matched pair group were very similar. The values and variables

were representative of each other at the starting point. Table 4 below shows that this is true across all variables.

Table 4. MEND vs Non MEND across all variables.

	PNES Patients	Mean	SD	p-value
Total ED Visits	MEND	5.13	6.70	.751
	NON MEND	5.78	9.55	
Psychotropic Medications	MEND	2.22	1.66	.050
	NON MEND	1.44	1.46	
Seizure Medications	MEND	1.09	1.17	.758
	NON MEND	1.00	1.24	
KEPRRA (Seizure Medication)	MEND	.125	.336	.328
	NON MEND	.218	.420	
Sleep Medications	MEND	.125	.336	.167
	NON MEND	.031	.177	

Note: P values are from t-tests.

Chi square tests were also ran to assess if there were any differences between the MEND vs non MEND participants in categorical variables including gender, marital status, and insurance type. Table 5 below shows how the variables are almost exact across the data of MEND patients versus the matched paired list. Additionally, of the 64 total participants (MEND vs non MEND), 68% of patients self-reported as

White/Caucasian, 15% self-reported as Hispanic, and 15% self-reported as African American. Age ranged from 18 years to 60 years old.

Table 5. MEND vs non MEND chi squared analyses.

<i>Group Crosstabulation</i>		Group			
		MEND	NON MEND	Total	
Insurance	Government	Count	15	18	33
		Expected Count	16.5	16.5	33
	Commercial	Count	17	14	31
		Expected Count	15.5	15.5	31
Gender	Female	Count	26	26	52
		Expected Count	26	26	52
	Males	Count	6	6	12
		Expected Count	6	6	12
Marital Status	Single	Count	19	25	44
		Expected Count	19	25	44
	Married	Count	13	7	20
		Expected Count	13	7	20

Aim Two: Emergency Department (ED) Visits

Aim two tested whether the PNES patients who completed the MEND program had a decrease in ED visits compared to the matched pair list of PNES patients who did not attend MEND. The hypothesis for the first part of aim two was that PNES patients

who have completed MEND would have a decrease in ED visits compared to those who have never received any treatment from the MEND program. A repeated measures ANOVA was run to compare the effect of MEND versus no MEND pre and post treatment on total ED and urgent care visits. Descriptive results are reported in Table 6 below. Table 7 shows the results of the repeated measures ANOVA.

Table 6. Pre and post MEND vs non MEND ED visits.

PNES Patients		Mean	SD	N
ED Visits PRE	MEND	5.13	6.70	32
	NON MEND	5.78	9.55	32
	Total	5.45	8.29	64
ED Visits Post	MEND	1.50	2.94	32
	NON MEND	4.38	8.03	32
	Total	2.94	6.17	64

Table 7. Multivariate test on ED visits.

	df	Mean Square	F	Sig.
EDVisits *PNESPATIENTS	1	45.13	4.73	.034
Error(ED Visits)	62	9.54		

Upon inspection of the repeated measures ANOVA assumptions, the outcome variable for ED visits had a few cases that were determined to be outliers. Therefore, 5

cases were reduced to a total number of ED visits no greater than 20. Specifically, three PNES patients from the non MEND matched pair group and two PNES patients from the MEND group were given a cut point of 20 to reflect that change. For the three PNES patients from the non MEND matched pair group, both pre and post time point corrections were made. For the two PNES patients in the MEND group, only pre time point corrections were made.

The repeated measures ANOVA indicated that non MEND versus MEND ED visits were significantly different after the MEND program, $F(1, 62), = 4.73, p = .034$. The findings revealed that ED visits subsequently decreased pre ($M = 5.13, SD = 6.70$) to post ($M = 1.50, SD = 2.94$) for PNES patients who completed the MEND program. Given this finding, it suggests that PNES patients who complete the MEND program do decrease in total ED and urgent care visits compared to those PNES patients who are not referred to the MEND program.

Therefore, the initial hypothesis that PNES patients who attend the MEND program would decrease in total ED and urgent care visits was supported. The repeated measures ANOVA indicated that there was statistical significance when comparing both groups, MEND and non MEND, with pre and post. Figure 5 below demonstrates these results further.

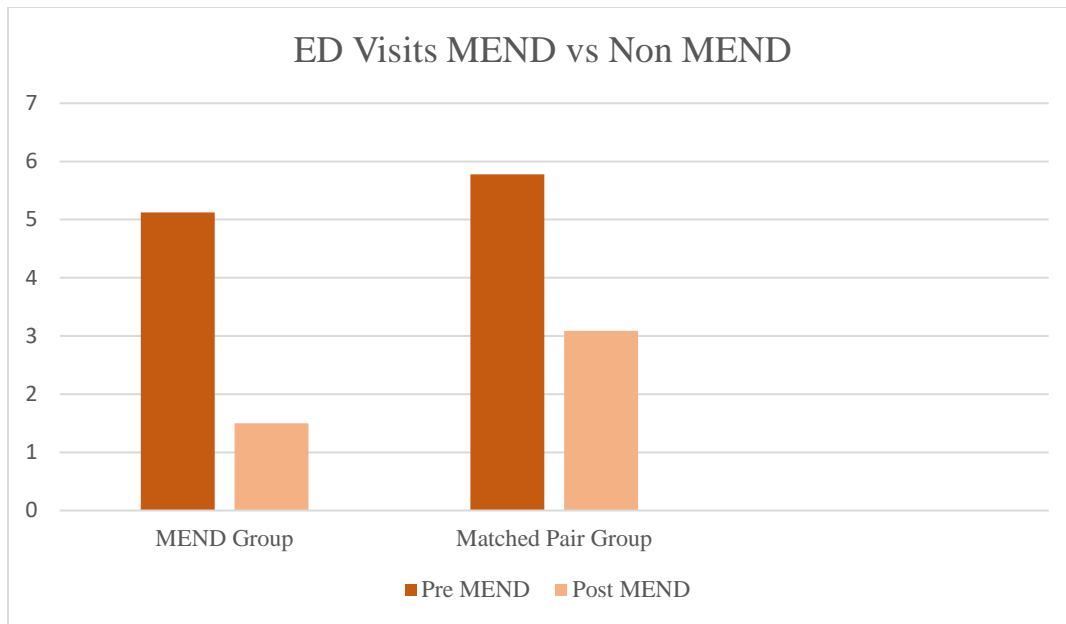


Figure 5. ED visits pre and post MEND vs matched pair control

Aim Two: Medications

Aim two also tested whether the PNES patients who completed the MEND program had a decrease in medications compared to the matched pair list of PNES patients who did not attend MEND. Aim two examined psychotropic medications, seizure medications, and sleep medications. The hypothesis for the second part of aim two was that PNES patients who completed MEND would have less medications in all three categories compared to those who have never received any treatment from the MEND program. A repeated measures ANOVA was run to compare the effect of MEND versus no MEND pre and post treatment on all medication categories. Descriptive results are shown in Table 8. Results of the repeated measures ANOVA are reported in Table 9 below.

Table 8. Pre and post MEND vs non MEND medications.

	PNES Patients	Mean	SD	N
Psych Meds PRE	MEND	2.22	1.66	32
	NON MEND	1.44	1.46	32
Psych Meds POST	MEND	1.81	1.31	32
	NON MEND	1.44	1.46	32
Sleep Meds PRE	MEND	0.13	.336	32
	NON MEND	.03	.177	32
Sleep Meds POST	MEND	.06	.246	32
	NON MEND	.03	.177	32
Seizure Meds PRE	MEND	1.09	1.17	32
	NON MEND	1.00	1.24	32
Seizure Meds POST	MEND	.53	.803	32
	NON MEND	1.00	1.17	32

Table 9. Multivariate tests on medications.

	df	Mean Square	F	Sig.	Partial Eta Squared
Psych Meds	1	1.32	1.75	.191	.027
Error (Psych Meds)	62	.756			
Seizure Meds	1	2.53	15.79	< .001	.203
Error (Seizure Meds)	62	.160			
Sleep Meds	1	.031	1.00	.321	.016
Error (Sleep Meds)	62	.031			

The repeated measures ANOVA indicated that non MEND versus MEND on psychotropic medications were not significantly different, $F(1, 62) = 1.75, p = .191, \eta^2 = 0.27$. This result showed that the psychotropic medications were trending towards significance, which may indicate a power limitation. However, prior to treatment at MEND, PNES patients had more total psychotropic medications ($M = 9.13, SD = 6.12$) than after completing the program ($M = 8.63, SD = 6.21$) while non MEND PNES patients had similar to post MEND participants on total medications ($M = 8.53, SD = 9.06$). Conversely, the results of the repeated measures ANOVA indicated that non MEND versus MEND for seizure medications were significantly different, $F(1, 62) = 15.79, p < .001, \eta^2 = 0.203$. This finding suggests that completing the MEND program

could lead to a decrease in seizure medications pre and post compared to the non MEND matched pair group. Lastly, the repeated measures ANOVA on sleep medications indicated that non MEND versus MEND were not significantly different, $F(1, 62) = 1.000, p = .321, \eta^2 = 0.016$.

A chi square test was also run to assess if there were any differences between the MEND vs non MEND participants in KEPPRA, a specific type of seizure medication. Results are reported in Tables 10 and 11 below.

Table 10. KEPPRA pre MEND.

<i>Crosstab</i>		KEPPRA PRE		
		NO KEPPRA	YES KEPPRA	Total
PNESPATIENTS	MEND	28	4	32
	NON MEND	25	7	32
Total		53	11	64
<i>Chi-Square Test</i>				
		Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	.988		1	.320

Table 11. KEPPRA post MEND.

<i>Crosstab</i>		KEPPRA POST		
		NO KEPPR A	YES KEPPRA	Total
PNESPATIENTS	MEND	31	1	32
	NON MEND	25	7	32
Total		56	8	64

<i>Chi-Square Test</i>			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	5.14	1	.023

Figure 6 below shows the medications pre and post MEND with the two groups (MEND vs non MEND).

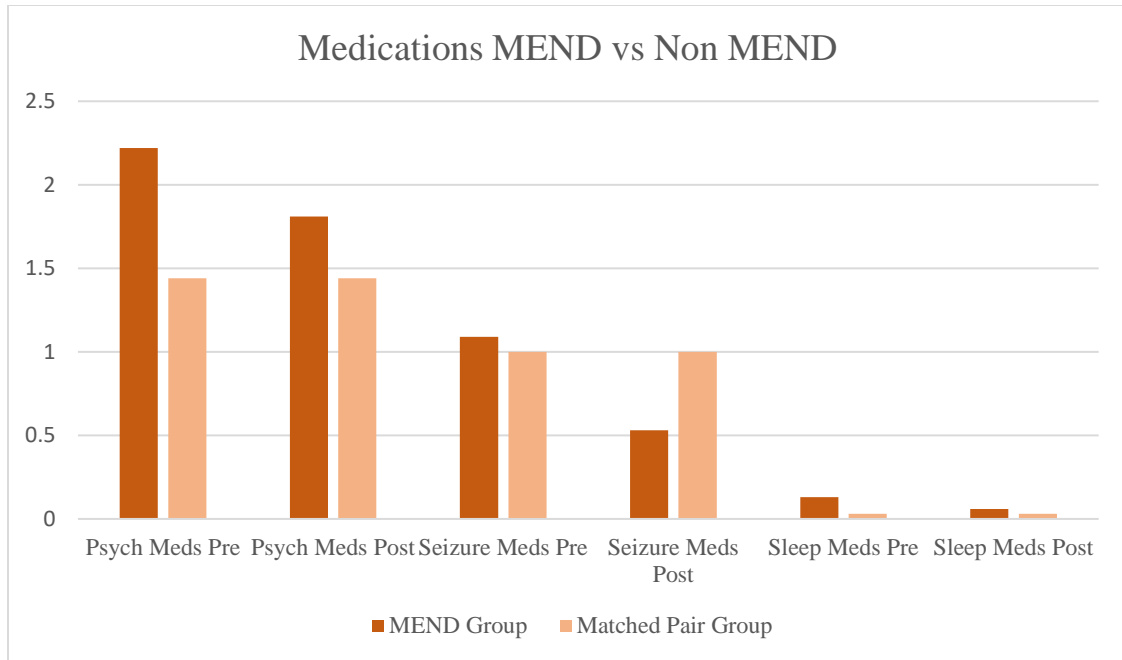


Figure 6. Medications pre and post MEND vs matched pair control.

Therefore, the initial hypothesis that PNES patients who attend the MEND program would decrease in medication was partially supported. The repeated measures ANOVA indicated that psychotropic medications and sleep medications were not statistically significant but seizure medications did show statistical significance when comparing both groups pre and post.

CHAPTER SIX

SUMMARY AND APPLICATIONS

As outlined in previous chapters, the purpose of this study was to evaluate PNES patients who completed the MEND program and compare their outcomes to PNES patients at LLUH who did not access MEND. This study utilized a retrospective design, and leveraged program data as well as LLUH EMR, particularly examining data from 2016-2021. Specifically, the goal of this study was to evaluate outcomes associated with the MEND program and PNES patients through looking at data from 1) all LLUH patients diagnosed with PNES between 2016-2021 and 2) a subsample of those patients who attended and completed the MEND program.

Findings

Aim One

For aim one of this study, there was two different sampling processes used. Aim one examined MEND only participants of the larger LLUH EMR list between the years of 2016-2021. The first part of aim one examined pre and post WHOQL data of 17 MEND PNES patients who completed the program. The second part of aim one used the EMR to examine frequency of Emergency Department (ED) visits and medications for 32 MEND PNES patients.

The results of part one of aim one indicated that there was statistical significance in WHOQL scores pre and post MEND program. In fact, there was statistical significance

in all domains of the self-reported WHOQL for PNES patients who completed MEND.

This was in line with the hypotheses:

H1: PNES patients who completed MEND increased in their total WHOQL score from pre and post MEND.

H2: PNES patients who completed MEND increased in their physical WHOQL score from pre and post MEND.

H3: PNES patients who completed MEND increased in their environment WHOQL score from pre and post MEND.

H4: PNES patients who completed MEND increased in their psychological health WHOQL score from pre and post MEND.

H5: PNES patients who completed MEND increased in their spiritual WHOQL score from pre and post MEND.

H6: PNES patients who completed MEND increased in their overall WHOQL score from pre and post MEND.

The results of part two of aim one demonstrated that there was some measured reduction in medications pre and post MEND, however, surprisingly, only seizure medications showed true statistical significance. This was partially in line with the hypotheses:

H1: PNES patients who completed MEND decreased in ED and urgent care visits pre and post MEND.

H2: PNES patients who completed MEND decreased in total medications pre and post MEND.

H3: PNES patients who completed MEND decreased in psychotropic medications pre and post MEND.

H4: PNES patients who completed MEND decreased in seizure medications pre and post MEND.

H5: PNES patients who completed MEND decreased in sleep medications pre and post MEND.

Aim Two

Aim two of this study involved match pairing the MEND only list to the larger LLUH PNES patient list, specifically comparing ED visits and medications. The 32 MEND participants were match paired with non MEND participants on demographic variables like age, ethnicity, marital status, and insurance. This design was done to examine the differences of PNES patients who complete MEND versus patients who did not.

The results of aim two indicated that non MEND versus MEND in ED visits were statistically significant pre and post. This was supported by the hypothesis:

H7: Those who have completed MEND had a decrease in ED visits compared to those who have never received any treatment from the MEND program.

The results of aim two indicated that non MEND versus MEND in medications were only statistically significant pre and post in seizure medications, whereas in all other medication categories were not statistically significant. Therefore, results were only partially supported by the initial hypothesis:

H8: Those who have completed MEND decreased in all medications compared to those who have never received any treatment from the MEND program.

Summation of Results

The results of aim one suggests that MEND is an effective psychosocial intervention on PNES patients, as pre and post outcome measures showed significant increase in health related quality of life evidenced by the WHOQL, and also showed significant reduction in ED visits and medications. The results of aim two showed that MEND was effective at reducing ED visits and medications when matched paired with non MEND PNES participants. Overall, the results indicate that MEND can be an effective behavioral health intervention for PNES patients.

Discussion

The results of this study indicated that PNES patients who completed MEND significantly improved health related quality of life through the self-reported measure WHOQL. They also had a significant decrease in ED visits and seizure medications. Additionally, when matched paired with the control group of PNES patients in the LLUH EMR who did not receive behavioral health treatment from MEND, the MEND only group had better outcomes than the non MEND group in number of ED visits and medication counts. While most medications were not statistically significant between the two groups (MEND and non MEND), there was still a measured reduction in all of the medications pre and post program. From the findings of this program evaluation, it preliminarily suggests that MEND seems to be a beneficial form of behavioral health

treatment to PNES patients.

Limitations

There were several notable limitations in the research. Firstly, this study was a retrospective design. As a result, the primary limitation was that there was an inferior level of evidence in choosing to do a retrospective study compared to doing a prospective study. For example, there was an absence of some data in the EMR, such as self-reported seizure activity, which made it difficult for proper and consistent data. Secondly, as this study utilized a matched pair control group, the risk of differences between the MEND only group and the matched pair group may have impacted the results, as choosing pairs that matched completely in all demographics were not always possible. This could have led to a possible self-selection bias, as this study needed both case and control group that were representative of the PNES patient population. This could make it challenging to assess how effective MEND was on PNES patients. Thirdly, this study had a small sample size, which indicates that the results of this study may not be generalizable. This could impact the results, as the findings from this study may not be truly representative of the overall PNES patient population. As the sample size was small, there was also a moderate potential for a Type II error. For example, some of the medications were trending towards significance but were not actually statistically significant. If this study had a larger sample size, results would have more than likely come back as significant.

Implications

These results represent the first demonstration of the application of the MEND program on PNES patients in measuring health related quality of life, ED visits, and medications. The results, however, were preliminary and cannot be generalized so easily. Despite the mentioned limitations, these results do suggest several theoretical and practical implications for MEND.

Future studies that evaluate the MEND program on PNES patients should take this study into account and add measures or other data that will substantiate the results found in this one. Conducting a prospective version of this study would be beneficial as well in order to assess the long term effects of PNES patients who complete MEND.

Clinical Implications

Despite treatment for PNES patients remaining controversial, Smith (2014) discusses how psychotherapy continues to be the best and most validated approach to working with this patient population. This study is aligned to previous research, in the emphasis of behavioral health intervention for PNES patients. While prior PNES studies have primarily used Cognitive Behavioral Therapy (CBT) as an effective psychological treatment for this patient population, evaluating the MEND program creates possibility of a different behavioral health treatment approach for PNES patients.

The MEND program is unique to current behavioral health literature on PNES patients in that it considers the inclusion and emphasis of family systems therapy, something that, to the best of our knowledge, no other study has included. It is not uncommon that PNES patients report high family dysfunction and interpersonal

relationships (LaFrance et al., 2011). Yet, there is limited research on the impact of family systems therapy on health outcomes for PNES patients. This study was unique in that the MEND program, a family systems based program, was evaluated.

In the field of marriage and family therapy, where the focus is on understanding a diagnosis and symptoms within the context of one's interactions and relationships, this current study lends support to the importance of examining the diagnosis and symptomology of PNES from a systemic lens. Additionally, this study offers support for future Marriage and Family therapists working with PNES patients, as PNES is much more than a somatic symptom disorder diagnosis and can frequently coexist with other comorbid mental health disorders (Dworetzky, 2016).

Recommendations and Future Research

The limitations of this program evaluation and study continues to point towards topics in PNES literature to be addressed in the future. As this study was a retrospective design with a matched case-control, future studies should take this study into account and use this research as a vehicle to conduct a prospective design if feasible.

Much work needs to be done before a full understanding and generalization of the application of the MEND program impacting PNES patients is established. Although this study supported preliminary PNES research, the study's most important contribution may be that it raised a variety of intriguing questions for future studies. Questions like, "How can the field of marriage and family therapy understand this patient population and work effectively with PNES patients?" Future research can be improved in a few ways: 1)

increasing the sample size of PNES patients in evaluating the effects of the MEND program and 2) using current study and research to create a prospective design

Conclusion

Despite these limitations, the present study has enhanced our understanding between completing MEND on ED visits, medications, and health related quality of life for PNES patients. This research can be seen as a first step towards integrating future research in evaluating the MEND program's application and effectiveness of working with PNES patients. The present research contributes to a growing body of PNES patient literature suggesting the connection between behavioral health services and improvement in PNES patients, particularly examining the efficacy of family systems therapy. Further research will be needed to determine the long term effects of the MEND program on PNES patients before generalized conclusions can be drawn.

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