Psychogenic Non-Epileptic Seizures: Arriving at Best Practices for Counsellors

by

Lorelei Wey

A Capstone Research Project submitted in partial fulfillment of the requirements for the degree of

Master of Counselling (MC)

City University in Canada

Vancouver, British Columbia, Canada

April 25, 2023

APPROVED BY

Ron Manley, Ph.D., R.Psych. (#0866), Capstone Supervisor, Counsellor Education Faculty

School of Health and Social Sciences

Laura Farres, Ph.D., R.C.C., Ch.PC., MPC., Faculty Reader, Counsellor Education Faculty

Abstract

Individuals with psychogenic non-epileptic seizures (PNES) straddle the two worlds of neurology and psychiatry and are often left to fall through the cracks. As such, this capstone paper provides a detailed description of this complicated diagnosis, as well as the numerous vulnerability traits which make a person more susceptible to this condition. This paper also explores the various forms of stigma these individuals encounter in their life, both inside and outside of healthcare. The traditionally used therapeutic approaches for this client population are explored, as well as other more current and less researched approaches, such as acceptance and commitment therapy (ACT) as well as somatic-based therapeutic approaches. Even though there is a lack of research using ACT and somatic-based modalities to treat PNES, there are numerous potential benefits using key interventions. Based upon synthesizing the current research in this field, an itinerary for a one-day psychoeducational workshop for counsellors is proposed using a trauma-informed and biopsychosocialspiritual approach.

Keywords: psychogenic non-epileptic seizures (PNES), acceptance and commitment therapy (ACT), somatic-based therapeutic approaches, trauma-informed, biopsychosocialspiritual.

Acknowledgements

I would like to thank several people for supporting me throughout this long but rewarding journey of completing not just this capstone paper, but also this Master of Counselling program.

I would first like to thank my husband Kelly who has been my cheerleader throughout this process and endured countless late-night ramblings on the topic of this capstone paper. I would also like to thank my two sons Charlie and Leo. Even though they joke about the endless hours I have spent sitting in my "office," which is also my closet, I can only hope that I have somehow demonstrated to them that anything is possible with a little determination and belief in yourself. I must also thank my sister Melody for happily grammar checking countless pages of this capstone paper, on short notice and with no complaints.

I would also like to thank Dr. Ron Manley for his keen insights, time, and gentle guidance for this capstone paper. I would also like to thank my second reader, Dr. Laura Farres for her keen insights. A big thanks to my EEG supervisor Ewa Kowalska for her unwavering support and encouragement throughout this entire process. Thank you also to my supervisor at Deltassist Julie Chadwick and the wonderful Deltassist team who have taught me so much professionally and personally.

Lastly, I would like to acknowledge the Covid-19 global pandemic. Like many others working in healthcare, this devasting world event caused me to pause and revaluate my life and how I feel I can help people the most. I am thankful that this realization brought me to City University and to the wonderful supportive folks of my cohort, whom I am lucky enough to also call my friends.

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Chapter 1: Introduction

This first chapter of this capstone project will provide a brief description of psychogenic non-epileptic seizures (PNES), based upon the current and existing research on this topic. This will be followed by stating the purposes and theoretical framework which will guide this paper, a description of what contributions this paper aims to add to the field, as well as identifying how this topic will fill a much-needed knowledge gap. Next, the writer's positionality to this topic will be described, followed by a definition of key terms. Lastly, an outline of the following chapters will be provided.

Overview of PNES

Your tests have all come back normal and there is nothing medically wrong with you is the message many people who suffer from PNES receive. These patients straddle the sidelines of neurology and psychiatry and are often left behind. Many people have a general understanding of epilepsy and seizures, however, PNES is complex and poorly understood by society, healthcare workers, as well as counsellors. As a result, these individuals' quality of life, the healthcare system and even one's community can be impacted (Robson et al., 2018). The diagnosis of PNES is often ignored or invalidated since it is not considered as serious as an epilepsy diagnosis.

PNES resembles an epileptic seizure but is thought to be psychological in nature (Brown & Reuber, 2016). A person who experiences PNES will present with symptoms that resemble a seizure, such as motor, sensory, and behavioural changes, as well as changes in nervous and autonomic system functioning (Reuber, 2008). This could be anything from presenting to an emergency room hospital with involuntary episodes of uncontrollable limb jerking and lip smacking to episodes of sudden loss of consciousness. This can be extremely difficult to diagnose since the symptoms resemble an epileptic seizure, and therefore misdiagnosis is common (Brown & Rueber, 2016). In fact, the average time it takes to receive a PNES diagnosis is seven years (Rueber et al., 2002). LaFrance and Benadis (2006) indicated that during the time it takes to obtain a PNES diagnosis, patients are often prescribed

antiepileptic drugs (AEDs) to the point of drug toxicity. They also explained that often patients with PNES are subjected to aggressive treatments to stop the non-epileptic seizures which can result in oversedation and intubation, and as a result, the impact on the PNES patient's health can be detrimental. LaFrance and Bendis also detailed how PNES patients typically undergo countless rounds of EEGs, neuroimaging, and hospital admissions which is frustrating and time consuming for the individual and costly to the health system with an estimated cost of $100,000 per person with PNES per lifetime in diagnostic tests, medications, and hospital admissions. Since it is a well-documented fact that 25-30% of all patients referred to Epilepsy centers have PNES, this has profound effects on the healthcare system and the costs required for these patients (LaFrance & Benadis, 2006; Turner et al., 2011).

The key difference between a seizure and PNES is that there are no changes in electrical brain activity as measured by an electroencephalogram (EEG) (Bowman, 1998). In order to accurately diagnose a PNES, the gold standard is video EEG monitoring where the patient is hooked up to scalp electrodes which monitor the brain activity, and the absence of ictal epileptic discharges during clinical events is confirmatory for PNES (Brown & Rueber, 2016; Fiszman et al., 2004).

Currently, there is no universally accepted and agreed upon unified etiological model to explain PNES, however, there are numerous well-documented risk factors (Baslet et al., 2015). People who experience PNES come from a variety of backgrounds and medical comorbidities (Brown & Reuber, 2016). According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), PNES is considered a subgroup of conversion disorders called functional neurological symptoms disorders (American Psychiatric Association, 2013). It is important to note that PNES-like behaviours can be willfully produced as manifestations in Factitious Disorder (American Psychiatric Association, 2013). For the purpose of this capstone, all PNES behaviours will be assumed to be involuntary and not willfully produced. Conversion disorders were first described by Freud in 1885 with his concept of hysteria, which he asserted was a response to emotional distress and trauma that could not be resolved with

psychic processes (Anzelloti et al., 2020). Freud was on to something, since there is now a wealth of research which demonstrates a connection between PNES and having a history of trauma and physical and sexual abuse histories (Bowman & Markland, 1996; Brown & Reuber, 2016). In fact, Fiszman et al. (2004) found that 15-40% of people who experience PNES have histories of trauma and abuse compared to the general population with a high percentage of these people also suffering from post-traumatic stress disorder (PTSD). Given the high rates of trauma by PNES patients, there are also sociocultural considerations with respect to this patient population since there is a strong correlation and unequal distribution of trauma amongst marginalized groups (Voith et al., 2020). Abubakr and Wambacq (2014) explain that the higher incidence of females found with PNES is due to the higher rates of physical and sexual abuse experienced by females than males. There are other contributing factors which Abubakr and Wambacq point out such as marginalized groups are more likely to have alcohol dependence, unemployment and be on disability benefits. There are also socioeconomic effects of having PNES since it is documented that this patient population is more likely to have welfare dependence (Mellers, 2005). In a study by Kristensen and Alving (1992), 55% of PNES patients were found to be on disability pension compared to 23% of epilepsy control patients. Nonetheless, given the numerous sociocultural factors at play, an intersectional lens needs to be used when approaching the topic of PNES.

PNES is further complicated since it is a well-researched fact that this population is known to suffer from a kaleidoscope of medical and psychiatric comorbidities (Turner et al., 2011). To prove this point, a study by Witgert et al. (2005) suggested that 95% of PNES patients have medical or psychiatric comorbidities compared to the general population. This can include physical/medical conditions without a known cause such as fibromyalgia or chronic pain (Benadis, 2005). PNES is also strongly associated with other psychological conditions such as anxiety, depression, and cluster B borderline personality traits (Beghi et al., 2015). It is well-documented that PNES patients are associated with chronic disability (Goldstein et al., 2010).

Another prevalent theme in the literature is the stigma these patients experience in the healthcare system from healthcare workers as well as the stigma they experience from friends, family, and society. Often these patients are told they their symptoms are not real and even worse, that they are attention seeking or "faking it" (Robson & Lian, 2017, p. 8). This can be damaging to hear, since to them their symptoms are very real. Feelings of shame, blame and humiliation are often reported by these patients and their families (Robson & Lian, 2017). At times, these patients are on the receiving end of belittling and disdainful medical-based jokes, which at times they are well aware of (Tolchin et al., 2016). Robson et al. (2017) studied the social factors that may affect the PNES patient's quality of life and found that perceived stigma associated with social functioning resulted in reduced health related quality of life.

The treatment for PNES is still largely unclear which could be due to a lack of knowledge of how to properly treat this population or a lack of resources. It could also be because most PNES patients are seen and diagnosed through the "epilepsy door," however, from there the pass off to mental health services is limited (Baslet, 2012, p. 595). Benadis (2019) states that most epilepsy centers who treat PNES do not typically have available mental health services, however, psychological treatment may be the most effective treatment.

Purpose Statements

The purpose of this capstone is to provide counsellors and therapists with a detailed description of what PNES is and in doing so, help reduce the stigma associated with this poorly understood diagnosis. This capstone paper also aims to add to the limited scholarly knowledge on this topic and provide more insights to help close this knowledge gap.

This capstone paper will also explore the therapeutic efficacy of what current counselling therapies are used to treat this condition, with a focus on acceptance and commitment therapy (ACT) and somatic-based therapies. Golstein et al. (2015) indicated that the gold standard counselling

treatment for PNES is cognitive behavioural therapy (CBT), therefore, the potential benefits of incorporating the mindfulness techniques of ACT in addition to core principles of CBT will be explored. A focus on somatic therapies such as somatic experiencing and sensorimotor therapy will also be examined since the research shows a clear connection between PNES and trauma (Brown & Reuber, 2016). Koven (2021) asserts that when healing people from trauma, one could try to heal it cognitively or emotionally, however the root is in healing the dysregulated nervous system and defensive systems of the body. Therefore, counselling individuals with a somatic-based therapeutic approach will also be explored.

As a result of synthesizing the clinical research in this area, this capstone will arrive at suggested best practices to counsel people with PNES in the form of a psychoeducational workshop for counsellors who have an interest in working with this demographic.

Theoretical/Conceptual Framework

This capstone paper will use a biopsychosocial approach when exploring what best practices to use when counselling individuals with PNES. This approach will be used since the current thought is PNES is a result of environmental, genetic, and neurological factors which act together in a perfect storm with psychological conditions (Asadi-Pooya, 2016). This also goes along with Gabor Mate's (2022) model of disease which will be used as a basis for this capstone. In this model, diseases or mental health conditions are not things that happen to a person or a separate entity but are, processes that occur based on what a person has experienced, whether that be from their environment, childhood, or the traumas they have experienced (Maté,2022).

A trauma informed approach will also be used when approaching this topic matter since the research is unequivocal in its connection between people who have PNES and who have also experienced trauma (Brown & Reuber, 2016). When thinking about what it means to use a trauma informed approach, Mate's definition of trauma will be used; "Trauma is not what happens to you, it is

what happens inside you" (Maté, 2021, 0.04). Along these lines, trauma has a well-known impact on a person's autonomic and sympathetic nervous system which can affect peoples' bodies and mental capacities profoundly (Dent, 2020). Recognizing the impact of trauma on a person's ability to cope and respond in daily life will be taken account when counselling this population.

Contributions to the Field

This capstone paper is significant since there is a lack of scholarly literature on PNES compared to epilepsy, despite a rising interest in the topic (Brown & Rueber, 2016; Wiseman & Rueber, 2015). By adding to the understanding of this complex condition, this will help to shine a light on the stigma this population faces in the healthcare system and society.

There is also a dearth of research on therapeutic modalities to treat PNES other than the traditional use of CBT. This could be since ACT and somatic therapies are emerging in popularity and research; thus, this capstone paper will provide a fresh perspective on what current counselling practices could be incorporated to be most useful to this population. This capstone project will help to fill the knowledge gap of this condition while also providing a much-needed framework and guidance for best practices in counselling with this patient population.

While researching for this capstone paper, one unexpected theme that emerged is the inconsistency and variation of terms used for this condition. For example, Wardrope et al. (2021) indicate that while the terms psychogenic seizures (PNES), pseudo seizures, functional seizures (FS), dissociative seizures (DS), conversion disorder with seizures, and non-epileptic attack disorder (NEAD) are the most frequently used terms, there are many other diagnostic labels used as well. They also wrote that this very topic of what to name this disorder is often hotly debated and disagreed upon by experts. They described how the terminology is not just academic but has far reaching implications on how patients understand and respond to their diagnosis as well as implications on how to navigate the healthcare system. The choice of diagnostic label could also potentially serve as a barrier to healthcare

services, and it could affect the available treatments and referral pathways (Wardrope et al., 2021). For example, if the word “seizure” were used instead of “events” this could potentially affect which specialist individuals are referred to (Wardrope et al., 2021, p. 107). This lack of consensus of what to call this disorder is, in *itself,* a knowledge gap. One thing is for sure and that is that language matters, and the labels given to people matter greatly, keeping in mind that one of the purposes of this capstone is to help reduce the stigma associated with this diagnosis. Wardrope et al. (2021) also pointed out the complexities involved with classifying and labelling people and how it can shape and impact an individual’s experiences. With all things considered, for the purposes of this capstone paper the term PNES will be used since it is the term currently used by the International League Against Epilepsy (ILAE) and the term most used in the current literature (Wardrobe et al., 2021). This is an area for future study and the ILAE has proposed creating a task force to establish a consensus diagnosis for PNES (Wardrobe et al., 2021).

Lastly, the trickle-down effect of this capstone is that with added mental health support for the PNES population through counselling, this could ultimately help to reduce the seizure frequency in PNES patients, which could have other trickledown benefits. This will ultimately reduce the load these patients pose on the healthcare system in terms of number of medical tests and healthcare workers involved and therefore ultimately reducing the healthcare costs of this condition and improve the individual’s quality of life. With reduced number of seizures of PNES patients, it will also help improve their health and this also means fewer unnecessary medications prescribed and fewer medical interventions needed for this patient population. It is important to note that using reduced seizure frequency in PNES patients as an outcome measure has been questioned by Reuber et al. (2003), and therefore an individualized approach to creating a client-specific counselling plan will be proposed with an emphasis on improving not just seizure frequency but also improving other PNES symptoms, such as emotional regulation and maladaptive behaviours.

Reflectivity and Positionality Statement

I feel as though I did not choose this topic, but rather it chose me. When I reflect, my interest in neurology and psychology likely started with my mother, who was diagnosed with a neurological condition, multiple sclerosis (MS), when I was a young child. During the time of writing this capstone she was also diagnosed with Alzheimer's – another heavy neurological diagnosis for someone still in their sixties. Another standout influence from my childhood was a good friend of mine who had frequent seizures at school. Kids in the nineties could be thoughtless and he was given the cruel nickname of "seizure boy." Over the years I have often thought about how demoralizing and truly awful that experience must have been for that friend. Fast forward to the present day and I am currently approaching this topic from the perspective of a healthcare worker with 15 years' experience of working directly with individuals with PNES. Specifically, my current occupation is a neurodiagnostic technologist, which is a fancy title to say that I perform electroencephalograms (EEGs) on people from newborn babies to comatose patients lying in the intensive care unit (ICU). An EEG is often the last test done on a patient to diagnose brain death and once this is determined often care is discontinued. This can be an emotionally draining job while also navigating family members who are typically in extreme distress at their loved one's bedside. My years of talking to patients and family members have brought me to the field of counselling where I now hope to make a difference in people's lives through listening to their stories.

I am also writing this capstone paper from the perspective of a white, cis-gender, woman of many privileges. For example, living in Canada with a career that provides me a comprehensive healthcare plan, I have the privilege of never having to pay out of pocket for medical expenses. I also live in a city with multiple large hospitals and access to high level medical care if I need it. I also have the privilege of being a physically healthy and able-bodied person who has rarely ever needed to seek

medical care for myself. Given my multiple social and cultural locations of privilege, my aim with this capstone paper is to approach this topic with a socio-cultural inclusive lens.

There are numerous reasons a person may be referred for an EEG but one of the main reasons is if a patient is suspected of having a seizure, or PNES. It is important to note that in many cases some individuals experience both PNES and seizures and it is difficult at times to discern which is which (De Barrios et al., 2018). Although I am interested in seizures, PNES hold a certain mystique for me.
As a neurodiagnostic technologist, I frequently record video EEG monitoring of patients who are experiencing PNES. At times, we admit them to special long-term monitoring (LTM) where we record video-EEG monitoring. I have personally witnessed the stigma these patients face directly, and indirectly. For example, I have witnessed healthcare workers smirk, make comments on their "performance," and laugh behind their backs due to the lack of knowledge and stigma these patients experience from healthcare workers who often have the preconceived notion that these patients are faking their condition in order to gain medical attention. I cannot help but feel like we can all do better to support these patients. It is from the perspective of witnessing the stigma and lack of mental health support that I am approaching this capstone paper. My hope is that my position as a healthcare worker will not bias the process of this capstone paper. My aim is that my unique perspective will bring a person-centered and compassionate lens to people who experience PNES.

Over the years I have often wondered what happens to these PNES patients after they leave the hospital. I have wondered if these patients ever seek counselling, and would that help? According to LaFrance et al. (2013) communicating a PNES diagnosis may stop PNES in the short-term, however ultimately appropriate psychotherapy is essential to stopping future episodes of PNES. Very often I see them return to the hospital time and time again - caught in an endless cycle of emergency room (ER) visits and hospitalizations. Unlike patients with epilepsy or seizures, there does not seem to be any concrete treatment, from what I have observed.

I have also observed over the years that patients with PNES have many challenges. And by this, I mean that they often have a myriad of medical comorbidities and very often they struggle with addictions and come from the lower socioeconomic walks of life. I have also observed that a relatively large proportion of them have experienced trauma. I have observed that if someone is experiencing PNES, they likely have many other stressors as well. These observations and experience could pose as a potential preconceived bias in this capstone project and so I will need to check and maintain awareness of this possible limitation within myself. For example, my experiences may bring me to assume that people with PNES must have experienced trauma or have some form of stressor in their life, however, this may not necessarily be true for all folks. It is possible that someone may have PNES who has not had these adverse experiences.

Since I feel a close connection to this patient population, and I come to the field of counselling with a unique awareness and education on the condition of PNES, I would like to be able to provide these clients with the most effective counselling possible.

Definitions of Terms

Antiepileptic Drugs (AED)

Medication given to help reduce or stop seizures by lowering the brains seizure threshold (Mayo Clinic, 2022). These are also referred to as anticonvulsants or antiseizure drugs (ASD) (Mayo Clinic, 2022).

Electroencepahlogram (EEG)

A diagnostic test for epilepsy and seizures that measures and records the electrical activity of the brain using scalp electrodes (Mayo Clinic, 2021).

Epilepsy

Defined by the International League Against Epilepsy (ILAE) as 1) as when a person experiences two or more seizures, at least 24 hours apart and is not brought on by any identifiable cause, 2) one

unprovoked seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years or 3) diagnosis of an epilepsy syndrome (International League Against Epilepsy, 2014).

Ictal

The period of time during an epileptic seizure (Anzelloti et al., 2020).

Neurodiagnostic Technologist

A technologist who is trained to perform EEGs as well as other neurodiagnostic testing.

Psychogenic Nonepileptic Seizure (PNES)

An episode where there are observable physical changes resembling a seizure, yet with no electrical brain changes (Bowman, 1998).

Seizure

A sudden and uncontrolled electrical disturbance in the brain which is typically accompanied by clinical changes such as an altered level of consciousness, movements, feelings and/or behaviours (Mayo Clinic, 2022).

Outline of Capstone Project Chapters

This capstone paper will be followed by chapter two which is a literature review with three sections. The first section will provide a detailed description of PNES based upon the current existing literature. The second section will provide an overview of the stigma experienced by this patient population, and in particular the stigmas experienced in the healthcare system by healthcare workers as well as stigma they may experience in society. The last section will provide an overview of what current therapeutic modalities are used in counselling this patient population, with a focus on ACT and somatic-based therapies. Lastly, as a result of synthesizing the clinical research in this area, chapter three will arrive at suggested best practices to use when counselling individuals with PNES.

Chapter Two: Literature Review

The previous chapter provided a brief description of psychogenic non-epileptic seizures (PNES) as well as stating the purpose of this capstone. As such, this chapter is divided into three parts, each with a focus on addressing one of the specific purposes of this capstone discussion. Part one provides a comprehensive description of PNES. This will be followed by part two which will describe and discuss a primary theme experienced in the lives of those with a PNES diagnosis, that of stigma. Lastly, part three provides a brief overview of current standard practice when working with clients with a PNES diagnosis.

Part 1: Description of PNES

The following section will provide an exploration of the PNES clinical presentation, diagnosis, impact on daily life and outcome. Following this is a description of documented vulnerability traits that are found to contribute to an increased susceptibility to PNES as a condition. This is followed by describing its prevalence, current treatments, and cultural considerations.

Clinical Presentation

PNES has a wide range of clinical presentations. A person experiencing PNES will present with changes in nervous and autonomic system functionality. These changes are observed in the symptom domains of voluntary motor, sensory, behavioural, and psychological changes. The American Psychiatric Association (APA) (2013) describes the presentation as including: sensory symptoms such as vision, hearing, and changes in skin sensation. Also described are common motor changes such as limb jerking, limb posturing, tremors, gait abnormalities, speech, or generalized weakness. The authors also highlight how dissociation such as avoidance or depersonalization is also a common symptom. There can also be changes in awareness, consciousness, or changes in memory (APA, 2013). With all these factors to consider, the diagnosis of conversion disorder requires the consideration of the “overall clinical picture” and not on one singular symptom (APA, 2013, p. 319). This can create challenges in diagnosis.

Diagnosis

Diagnosing PNES is challenging and can mimic many other disorders, and therefore requires sophisticated EEG monitoring equipment as well as trained EEG technologists. The current definition of PNES is understood as a sudden and involuntary episode that resembles as seizure, but unlike a seizure, there are no electrical changes in brain activity (Bowman, 1998). Essentially, PNES resembles an epileptic seizure; however, is thought to be mediated by psychological factors since no organic cause has been identified (Bakvis et al., 2009). To accurately diagnose a PNES, the gold standard is video EEG monitoring where the patient is hooked up to scalp electrodes which monitor the brain activity, and the absence of electrophysiological correlates during an episode is confirmatory for PNES (Brown & Rueber, 2016). In order to accurately diagnose PNES, the patient is hooked up to video EEG and a typical clinical event is recorded, with an absence of ictal epileptic discharges recorded (Fiszman et al., 2004). In addition, nonepileptic causes for the events also need to be ruled out such as drug intoxication, migraines, movement and sleep disorders, syncope, and metabolic disorder (Fiszman et al., 2004). Kozlowska et al. (2017) highlight how it can be damaging to diagnose a patient with PNES without a thorough medical examination ruling out other conditions which could mimic PNES. Along these lines, a PNES diagnosis also requires ruling out other mental health disorders such as anxiety attacks or flashbacks in the form of PTSD (Elger & Reuber, 2003). Furthermore, Anzelloti et al. (2020) assert that a true diagnosis for PNES requires no epileptiform activity before, during or even after the ictal event. Diagnosis is relatively straight forward with the use of trained EEG technologists and video-EEG monitoring, however, despite this misdiagnosis and delays in diagnosis are common.

One challenge with diagnosing PNES, is deciphering it from epilepsy. Along these lines, the International League Against Epilepsy (2022) has classified PNES as one of the 10 most critical neuropsychiatric conditions associated with epilepsy since there is very often a dual diagnosis of both epilepsy and PNES, which can be challenging for physicians to diagnose. To back this up, Benadis and

Hauser (2000) point out that 10-12% of individuals with PNES have co-occurring true epilepsy seizures. PNES symptoms resemble an epileptic seizure since the behavioral disturbances can often be dramatic and alarming for bystanders and very easily mistaken for epilepsy (Brown & Rueber, 2016). Due to the complicated diagnosis process, the average time it takes to receive a PNES diagnosis is seven years (Rueber et al., 2002). This delay in diagnosis has been shown to result in poor prognosis (Mellers, 2005). Ansellotti et al. (2020) describe how the cost of this challenge can result in harmful and unnecessary increase in dosages of antiepileptic drugs (AED) as well as misdiagnosis. In fact, there is an estimated 75% of PNES patients received AEDs prior to having a PNES diagnosis (Szaflarski et al., 20003). This can be harmful to patients due to the harmful side effects of many of these medications which can impact patient's day to day life (Ansellotti et al., 2020). A misdiagnosis can also cause iatropic hazards such as intubation when a patient experiences pseudostatus epilepticus due to medication induced respiratory arrest (Pakalnis et al., 1991). Ansellotti et al. also describe how one in four to five patients admitted for video-EEG monitoring who are thought to be suffering from medication resistant refractory epilepsy are found to have non-epileptic seizures. Cuthill and Espie (2005) also point out the psychosocial repercussions of a misdiagnosis of PNES in that the psychological needs of PNES would not be addressed. The APA (2013) also highlights how some people may experience episodes resembling PNES in some cultural and religious rituals. They explain that if the episode is not causing distress and is explained by the cultural context then a diagnosis of PNES would not be appropriate. Despite the numerous challenges with diagnosing PNES and avoiding unnecessary harm by delaying or misdiagnosing a client, there can be further challenges when there is no access to EEG monitoring to aid in diagnosis.

Many countries and people around the world have limited access to EEGs and therefore other factors can aid in a PNES diagnosis. Access to EEGs is often limited to larger urban center hospitals with limited availability in rural locations. Therefore, in order to supplement a PNES diagnosis, an accurate

patient history is essential (Anzelloti et al., 2020). It is also important to obtain detailed witness and observer accounts of the events, and a video recorded on a phone can be very important as well (Reuber et al., 2002). It is also important to conduct a thorough neurophysiological investigation (Cuthill & Espie, 2005). Even though PNES may resemble a true epileptic seizure, in a clinical presentation there are tell-tale signs that aid in deciphering between the two. For example, the APA (2013) describes how inconsistency in a neurological examination can be one sign. Distractibility can be another giveaway. For example, if the tremor is stopped by distracting the patient, it could be considered indicative of PNES (also described is the presence of closed eyes during PNES). Nonetheless, the majority of PNES symptoms seen are not willfully produced although some studies show that symptoms of PNES are more suggestible than epileptic events (Barry, 2000). Benadis (2005) discusses how in many instances it may be helpful to use suggestion or provoke a seizure episode in order to aid in the diagnosis. However, Benadis points out there are ethical objections and controversy to this practice despite its usefulness in diagnosis. Despite the complexities in a PNES diagnosis, there are further intricacies in its classification.

In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V), PNES is classified under a subgroup of conversion disorders called functional neurologic symptom disorder (American Psychiatric Association, 2013). Whereas, in the 10th revision of the *International Classification of Diseases* (ICD-10) (World Health Organization, 1993), PNES is classified as a dissociative disorder under dissociative convulsions. It is worth noting that there is continued debate with PNES classification since Bowman and Markland (1996) have recommended that PNES be reclassified from conversion to dissociative disorders given the high prevalence of histories of PTSD and childhood trauma in those with PNES. Both the DSM-V and ICD-10 specify that PNES is related to psychological stress factors (Benadis, 2005). These classifications are such that the symptoms are considered involuntary, however, some manifestations of PNES may be willfully produced and in those cases may fit more into the factitious disorder or Malingering (Reuber et al., 2002). Nonetheless, both the DSM-V and ICD-10 definitions

highlight the generally accepted concept that PNES results from an accumulation of various forms of psychological distress, that is expressed somatically (Bowman et al., 1999). This can result in a variety of impacts on a person's life.

The Impact of PNES on Daily Life

An individual living with PNES reports a variety of impacts on their life ranging from some people living happy and meaningful lives, whereas others report a range of negative impacts, while other reports it to be simply an inconvenience (Rawlings & Reuber, 2016). Along these lines, the majority of people with PNES have significant social and personal challenges (Novakova et al., 2015). Rawlings and Reuber (2016) also described how people felt isolated, unmotivated and had a decreased social life. The authors also report feelings of grief and loss of independence and feeling like a burden to their family members. The loss of a driver's license creates further dependence on others. Reuber et al. also tells us unemployment is another common complaint as well as financial stressors. The impact on the life of a PNES client is profound and can result in negative outcomes.

Outcome for People Living with PNES

Generally speaking, the mortality rates and quality of living outcome for PNES clients is often poor. In addition, Benadis (2005) reported morbidity rates to be high which could be attributed to underlying medical comorbidities. Despite this, Benadis reports 40-70% eventually become seizure free. Interestingly, Duncan et al. (2018) performed a study in Scotland and found that patients with PNES had a premature mortality rate compared to the general population even if the cause of death was not seizure related. The authors also wondered if the increased mortality could be due to a missed epilepsy diagnosis since people can have both conditions. This study also found that PNES patients were more likely to engage in self-harm or suicidal ideation. A PNES diagnosis can have clearly impact a person's life in a variety of ways and therefore it is important to be aware of what experiences can make a person more vulnerable to this condition.

Vulnerability Traits

The current understanding of PNES is still in its early stages and there is no agreed upon etiological model. Nonetheless, numerous characteristics have emerged from a literature search of vulnerability traits, which could render a person more vulnerable to developing PNES. These dimensions include: An association with traumatic stress, dissociation, difficulties in emotional processing, anxiety, psychiatric and medical comorbidities, gender, society, and family factors (Baslet et al., 2015). These vulnerability traits will be discussed in the following paragraphs.

Trauma. Trauma is the most robust correlate and commonality amongst clients with PNES. There is a well-documented connection of patients with PNES having suffered trauma, physical, emotional, and sexual abuse histories (Bowman & Markland, 1996; Brown & Reuber, 2016). In fact, 15-40% of PNES have experiences of trauma and abuse compared to the general population (Fiszman et al., 2004). Some estimates are higher with 85-100% of people with PNES having experienced trauma and adversity compared to the general population (Brown & Reuber, 2016). These stats show some variation; however, the association is real. As a result, post-traumatic stress disorder (PTSD) is frequently found in this patient population (Bowman & Markland, 1996). Despite the strong association between trauma and PNES symptoms, is important to note that a conversion disorder diagnosis can still be made even if the patient does not have a history of experiencing trauma (American Psychiatric Association, 2013).

There is also a strong correlation with clients with PNES experiencing childhood trauma. For example, people with PNES have higher than usual rates of childhood trauma and higher scores on Adverse Childhood Experiences (ACE) (Stone et al., 2004). It is also reported that PNES often occurs when childhood trauma is followed by common adult trauma such as sexual assault, head injury, or even after childbirth (Bowman, 1999). Reuber et al. (2002) tells us that in some studies 85-100% of PNES patient have experiences with childhood trauma, however, the prevalence varies depending on the definition of

trauma used. Kaplan et al. (2013), found that childhood trauma was more prevent in PNES patients than those with epilepsy, however, interestingly, those with epilepsy also have higher rates of childhood trauma than the general population. One prevalent symptom related to PTSD which is common in PNES is dissociation.

Dissociation Tendencies. Dissociation is another commonly reported PNES symptom. The most comprehensive study on this topic was done by Hendrickson et al. (2015), who found that 61.4% of 223 patients with PNES reported symptoms of detachment and disconnection immediately before, during and after a PNES seizure. Along these lines Rusch et al. (2001) also found the use of avoidance, denial, and escape were common coping mechanisms for people living with PNES. The DSM-V defines dissociation as "a disruption of and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control and behavior" (American Psychiatric Association, 2013, p. 291). This definition highlights the spectrum that dissociation can take. Furthermore, dissociation has also been thought to be split into subgroups of depersonalization, derealization, identity dissociation, emotional constriction, memory disturbances and disengagement (Briere et al., 2005). The presence of dissociation tendencies in PNES cannot be ignored.

Emotional Processing. Roughly one third of PNES patients have difficulties in emotional processing, also called alexithymia. This is defined as difficulty recognizing, describing, and perceiving their own emotional states (Beghi et al., 2015; Kaplan et al., 2013). Clients with PNES are often unable to recognize their own emotional distress which Kaplan (2013) reasons is one of the reasons this population does not often seek psychological treatment. Kaplan also describes how people with PNES can confuse their internal distressing thoughts and feelings as external conditions - such as physical illness. There are also emotionally avoidant tendencies in clients with PNES (Bakvis et al., 2011). Some theorists wonder whether PNES patients actively avoid emotions, or if rather they have heightened

awareness of their own bodily sensations (Brown & Reuber, 2016). Even though not all clients with PNES have difficulties with emotional processing, it is widely reported.

Anxiety. The most prevalent medical comorbidity people with PNES have is anxiety. Studies show up to 49% suffer from anxiety (Novakova et al., 2015). As such, Rusch et al. (2001) describe how at times acute anxiety and panic attacks are mistaken as PNES. Symptoms of lightheadedness, nausea, dizziness, and muscle tremors are often attributed to neurological causes, instead of typical anxiety symptoms such as shortness of breath or increased heart rate. Brown and Reuber (2016) also explain how a disproportionate number of PNES patients report frequent panic and anxiety associated with their attacks, however, these sensations are not always recognized as anxiety. Furthermore, hypervigilance or a having a sense of perceived threat is another commonly reported symptom of PNES (Bakvis et al., 2009). Even though anxiety is the most common medical comorbidity associated with PNES, there are numerous other well documented associations with other medical and psychiatric conditions.

Other Medical Comorbidities. It is a well-researched fact that patients with PNES often have a kaleidoscope of medical and psychiatric comorbidities (Turner et al., 2011). In fact, a study by Witgert et al. (2005) suggested that only 5% of PNES patients do *not* have medical or psychiatric comorbidities. Specifically, PNES clients are more likely than the general population to have cluster B borderline personality disorder and suffer from depression (Beghi et al., 2015). They are also more likely to live with medically unexplained conditions such as fibromyalgia and chronic pain (Beghi et al., 2015). Substance addictions such as alcohol misuse is also higher with the PNES population than the general population (American Psychiatric Association, 2013). Having an awareness of the variety of medical comorbidities associated with PNES will help in treatment.

Women. One notable trend found in the literature, is more women experience PNES than men. In fact, it is undisputed that 75% of people living with PNES are women, according to Rosenbaum (2000).

He explained this by describing how women tend to use dissociation as a coping mechanism to distress, whereas men use aggression. Rosenbaum also posited that women use PNES as way to express subconscious anger and fears which are not encouraged for women to do. It could also be the added cultural pressures women face in today's society. The higher proportion of females is also postulated to be due to the higher incidence of childhood trauma in females, which is a well-established correlate of PNES (Kaplan et al., 2013).

Social or Family Conflict. There are also significant social stressors reported by clients with PNES. To back this up, in a study of adolescents and children with diagnosed PNES, 44 % reported significant family stressors such as recent divorce of parents, or the recent death of a family member (Wyllie et al., 1999). Bowman et al. (1999) also reported that family stressors can be a common vulnerability factor for PNES. The authors also described how other societal stresses have been reported to contribute to PNES such as work stress or lawsuits. It is important to note that Lancman et al. (1994) found that one fifth of PNES patients had no obvious family or societal stressors. Despite this, family and societal stressors are another vulnerability factor of PNES.

Epidemiology. The prevalence of PNES is well documented. Similar to a scoliosis diagnosis, 2 - 33 per 100,000 of the general population will have a PNES presentation (Anzellotti, 2020). More specifically, PNES patients make up about 25-33% of suspected seizure patients seen in epilepsy centers (Carson et al., 2012). With this high number of hospital admissions, clients with psychogenic symptoms make up 12-18% of neurology clinic visits (Reuber, 2008). This results in as many as 10% of all medical tests (Benadis, 2005). PNES is mostly considered a condition of young adults ranging from 15-30 on average, however, it has been found in children and seniors as well (Reuber et al., 2002). PNES clients make up a high proportion of hospital and clinic visits, which results in high healthcare spending. Therefore, it is vital to consider which best treatments are available for this population. In summary, the prevalence of people living with PNES is significant.

When considering the high incidence of PNES, it is also worth highlighting that since a significant portion of this population are often unemployed and require disability or welfare dependence, these patients often are unable to seek medical care if they do not have access to it (Kristensen & Alving, 1992; Mellers, 2005). It is also worth noting that the majority of the studies found in this capstone paper were of patients who had access to healthcare facilities. Therefore, there is the possibility that there could be a higher incidence of people living with PNES since there are individuals from marginalized communities who do not have access to healthcare services, especially in countries where there may be limited access to neurology departments with EEG and diagnostic testing (Anzellotti et al., 2020).

Current Treatment and Management

There is currently no universally agreed upon treatment plan for PNES. According to LaFrance and Barry (2005), there are no guidelines on how to treat the PNES patient population due to a lack of clinical trials. Benadis (2019) describes the treatment for PNES as a "vexing challenge" since most health centers, even ones who specialize in epilepsy and PNES, do not have appropriate mental health care to treat this population (p. 1). Treatment options for PNES clients are limited and because of this, Benadis reported the outcome for this population to be poor. Since most of these individuals are initially treated through the "epilepsy door", they are initially seen by a neurologist (Baslet, 2012, p. 595). Therefore, this diagnosis requires collaboration between neurology and psychiatry. It is unfortunate that most epilepsy centers who treat PNES do not typically have available mental health services, since psychological treatment may be the most effective intervention for PNES (Benadis, 2019).

Cultural Considerations

During the course of this literature review there was a noticeable lack of research found into cultural considerations of PNES, meaning, is this a condition that is universal in all countries and cultures? However, one study was found by Asadi-Pooya et al. (2019) who conducted an international

cross cultural study using participants from Iran, Brazil, Venezuela, and Argentina and found the demographics to be similar in all countries in that patients were predominantly female. One interesting finding was that participants from Iran experienced more severe clinical symptoms which the researchers posit was result of "greater emotional repression for cultural and social reasons" (p. 8). This is an area that warrants further future research. It is also important to note that psychotherapy treatment for PNES is a privilege of those in the developing world (Asadi-Pooya et al., 2019).

Part 2: Stigma and PNES

The experience of stigma is well documented in individuals with PNES (Robson & Lian, 2017). In fact, stereotypes, and discrimination of those with mental illness is well researched, however, the perspectives of those with a mental illness is lacking in research (Fox et al., 2018). During the research of this capstone four themes emerged in terms of stigma experienced by patients with PNES: (1) the term itself, (2) stigma associated with the diagnosis, (3) stigma from the healthcare system, and (4) societal stigma experienced. Another area for future study would be the addition of culture as it pertains to stigma and PNES which is another gap in knowledge (Annandale et al., 2022). An underlying intentionality in providing an expanded discussion of PNES is to add to the current gap in professional knowledge and general awareness of the condition and the related mental health considerations. The aim is to potentially reduce the experience of stigmatization for the individual with this condition.

Stigma with the Term PNES Itself

There are many terms and labels given to clients with diagnosed PNES. These include: Pseudo seizures, functional seizures (FS), dissociative seizures (DS), nonepileptic seizures (NES), nonepileptic attack disorder (NEAD), hysterical seizures, and non-epileptic attacks (Cuthill & Espie, 2005). With this variety of labels, comes an ongoing debate with no consensus on what to call PNES. Along these lines,

Annandale et al. (2022) conducted a review of 70 studies of PNES including data from 85 countries and found that overall, there is no consensus on what to name this condition.

One of the reasons it is so challenging to label this condition, is because most of these terms use stigmatizing and shame producing language. For example, the term PNES in itself could be considered stigmatizing since the word *psychogenic* implies that something is not real, when in fact, PNES is a real condition. Shame is also experienced by PNES patients when delicately worded non-labels are used, such as *non-epileptic* seizures which implies that their condition is less real (Myers et al., 2022). Hansen et al. (2020) described an article in which PNES is referred to as "false seizures" and how offensive this could be since it implies that the condition is not true (p. 684). With all things considered, perhaps *functional* seizure is likely the most neutral and least stigmatizing term. However, many clients report confusion and loss of legitimacy after being given this diagnosis since the language implies that "nothing is wrong" (Hansen et al., 2020, p. 684). One thing is for sure and that is that language matters; therefore, the label and term that is used to classify and name different health conditions clearly matters.

The conundrum of what to call PNES has other considerations. Keeping in mind that the majority of PNES research uses a biopsychosocial framework to describe PNES, Hansen et al. (2020) posit that biological, psychological, and social aspects should be incorporated into the diagnostic label. The authors highlight that the main purpose of the label should be to accurately describe the disorder with disregard for the impact of that label on the client. On the flip side, other researchers emphasize that the language and terminology used should take into consideration the impact of stigma on the individual (Kelly et al., 2016). Kelly (2004) wrote that the language used to label conditions should be "explicit, precisely defined, and used consistently to aid unambiguous clinical and scientific communication" (p. 79). Therefore, since the majority of current literature uses the term PNES and this is the term recommended by the International League Against Epilepsy (2022), PNES is the term chosen for this capstone project - after careful and thoughtful consideration.

The term given has other impacts other than stigma. The term and label given to conditions can also open doors to resources. A universal term for the condition also encourages government funded research, policies, and clinical studies (Annadale et al., 2022). This point is furthered by Kelly who explains that the terms and labels given to conditions has implications for treatments access and clinical care. For some clients, the name given can provide support systems they may not have access to otherwise. The label given also affects how clients with PNES service and react to their diagnosis.

Stigma Associated with the Diagnosis

There is also stigma and shame with the diagnosis of PNES, and all that is implied with this complex and relatively unknown condition. The experience of stigma for people with PNES is described by Annadale et al. (2022) as two-fold since clients have the stigma of having a mental illness as well as the stigma associated with a seizure disorder. It is important to note that the experience of having PNES is found to be far more stigmatizing than an epilepsy diagnosis since epilepsy is considered a more medically acceptable condition, and something that cannot be controlled whereas PNES has a misconception that it is under voluntary control (Reuber et al., 2002). The diagnosis of PNES is fraught with stigma which can affect how clients react to their diagnosis.

Myer et al. (2022) describes how shame can impact how clients understand and react to their PNES diagnosis. The authors describe how people living with PNES often experience feelings of shame when they are given the diagnosis since it is framed as a psychological condition for attention seeking reasons. They also describe a case study of a woman who spent years undergoing medical tests and was finally given the diagnosis of PNES. This resulted in her feeling great shame since she was worried her family would think that she had wasted years of medical tests when she had only a psychological condition. Stigma can also influence how clients engage in psychological treatment in a meaningful way (Myer et al., 2022). It is important to consider the repercussions of the diagnosis of PNES.

The experience of stigma and shame in the healthcare system can also affect PNES symptom progression. Myer et al. (2022) describe how the emotion of shame itself contributes to the manifestation and perpetuation of PNES by influencing the emotional, cognitive, and behavioral elements of PNES. The patient's experience is known to have wide-ranging implications for health outcomes, patient safety, and the allocation of resources (Robson & Lian, 2017). Some clients with PNES experience internalized stigma, which can result in delayed and poor treatment and reduced treatment adherence (Fox et al., 2018). Tolchin et al. (2016) assert that it is "morally irrelevant" whether or not seizures are psychological or epileptic in etiology since all patients require the same amount of attention, empathy, and compassion (p. 27). The experience of stigma in the healthcare system can be profound.

Stigma from Healthcare

The most commonly reported experience of stigma for clients with PNES is their experiences in the healthcare system and in particular, with healthcare professionals. Robson and Lian (2017) conducted an anonymous study of 135 people living with PNES, and asked what challenges and consequences these people face when interacting with health professionals. The researcher found that there was a breakdown in the patient and healthcare provider relationship with reported lack of awareness and minimal access to resources about PNES. These individuals with PNES and their families also reported feelings of "shaming, blaming, humiliation" from the healthcare system (p. 1). Other participants reported health professionals did not listen to them, disrespected them, or suggested that the episodes were caused by voluntary control. This disregard for the patients resulted in patients reporting "feeling 'horrified', 'hopeless' or 'traumatized'; and for some, had even 'resulted in suicide attempts'" (p. 9). When asked to identify the worst experience the participants had in healthcare, many struggled to identify just one because there were so many to choose from. Furthermore, PNES patients are often on the receiving end of belittling and disdainful medical based jokes (Tolchin et al., 2016). Even

though Pretorius and Sparrow (2015) found that interactions with medical professionals were challenging, they were also found to be the main resource for PNES clients, which highlights the key role they play.

Stigma from Society

People living with PNES experience stigma from society in a variety of ways. Robson et al. (2017) studied the social factors that may affect the PNES patient's quality of life and found that perceived stigma associated with social functioning resulted in reduced health related quality of life. In line with this, Karterud et al. (2016) studied females with PNES between 14 and 24 years and found that the participants perceived legitimacy of their illness was directly correlated with how much they participated socially or isolated themselves. The researchers found that individuals with PNES often isolated themselves and concealed their diagnosis in order to prevent stigma and embarrassment in social situations. Pretorius and Sparrow (2015) found that fear of having unexpected seizure in public is also a central worry for PNES clients. They also explained the stigma people feel from bystanders who may treat them differently, simply due to their condition. The authors also found that at times patients have to give up their employment or education since their environments are not suited for their condition. The lack of public awareness contributes to PNES patients feeling of social isolation (Rawlings & Reuber, 2016)

People with PNES also experience stigma within their family. Pretorius and Sparrow (2015) explain how clients try to hide their condition from loved ones, especially young children, in order to not scare or upset them. The family may also want to protect their loved ones from activities where they could be harmed and so restriction of activities is commonly reported (Reuber et al., 2002).

There is also stigma within the social structures of society. Fox et al. (2018) describe the societal effects of stigmatization which results in stereotypes and discrimination. This has the trickle-down effect of lack of policy support and social rejection. It is also important to consider intersectional contributing

factors such: race, socioeconomic factors, gender, disabilities and how these may contribute to the experience of stigma people experience by society.

Part 3: Therapeutic Approaches to Treat PNES

This section will begin by describing the most common challenges and barriers people with PNES encounter when engaging in psychotherapy. This will be followed by a brief description of the most used therapeutic modalities and clinical approaches to treat PNES. This will not be an exhaustive review but rather provide a brief description of the rationale and evidence for using these approaches to treat people living with PNES. With a comprehensive literature review the current most commonly used psychotherapy techniques to treat this population are cognitive behavioural therapy (CBT), psychoeducation, psychodynamic therapy, group therapy and eye movement desensitization and reprocessing (EMDR). This overview will be followed by a more in-depth exploration of two more recent modalities and their utility in treating PNES: ACT and somatic based therapies. The underlying purpose of furthering a comprehensive discussion of current and potential therapeutic approaches is to create a standard of professional practice that effectively synthesizes relevant material in an effort to meet the needs of a client base involving a PNES diagnosis in a manner that is sensitive to the needs of a specific individual. It is important to remember that PNES symptom improvement may not be defined as freedom from seizures since this may not be possible for all individuals, therefore improved overall quality of life should be emphasized.

Challenges with Engaging in Psychotherapy

One challenge encountered when treating PNES, is encouraging individuals to actively engage in psychotherapy. Tolchin et al. (2020) describe how this population has low adherence to psychotherapy treatment since they often have limited insight into their own condition. The authors explain that despite evidence supporting the benefit of psychological treatments for PNES, most patients do not complete psychological treatment. Tolchin et al. posit that PNES patients with additional mental health

comorbidities such as depression and PTSD have even less adherence to psychotherapy treatment. This could be explained by Wyatt et al. (2014), who found that people who were referred to psychotherapy were perceived as having mental health problems and were worried about attending. There is also a lack of understanding about what psychotherapy could provide, which can influence the therapeutic expectations. Furthermore, there is a lack of research which explores patients' perceptions of psychological treatment for PNES (Wyatt et al., 2014). Improving awareness and knowledge of the benefits of psychotherapy for PNES could help in increasing treatment adherence.

The common barriers to treatment for PNES patients include ambivalence about their diagnosis and poor clinician communication (Tolchin et al., 2020). To mitigate this challenge, Tolchin et al. (2020) recommend using motivational interviewing (MI) as a strategy to target ambivalence about behavioural change as well as increasing motivation and adherence for treatment. Tolchin et al. (2020) described a clinical case vignette of a 37-year-old with diagnosed PNES who was reluctant to engage in psychological treatment. The researchers used MI to help decrease the client's ambivalence for treatment in order to attend a mindfulness-based psychotherapy session. Even with no-showing or cancelling half her scheduled sessions after four months, she showed a 90% reduction in PNES frequency and was able to function in her daily life much better. Using an individualized and person-centered approach can help PNES clients engage with psychotherapy.

Cognitive Behavioural Therapy (CBT)

The current gold standard psychotherapy treatment for PNES is CBT (Goldstein et al., 2015). This is also emphasized by Anzelloti et al. (2020) who explains CBT has the most "robust and experimental and clinical evidence of efficacy" (p. 10)**.** Goldstein and Mellers (2006) explained that premise for using CBT is the assumption that PNES events are dissociative responses to arousal when a person is placed in a stressful situation which invokes fear. CBT focuses on the cognitive and behavioural responses to a stressful situation; therefore, one limitation of CBT is that it does not address a person's historical

childhood trauma which may be contributing to the PNES episode (Gutkin et al. 2021). The rationale then for using CBT to treat PNES is to encourage awareness and coping when confronted with stress, which may evoke thoughts, feelings, and emotions which progress to the resultant seizure episode.

CBT has a wealth of empirical studies proving the efficacy of use in treating PNES. For example, LaFrance et al. (2020) studied PNES patients treated via clinical video telehealth with a manualized CBT approach over 12- sessions and found a 46% reduction in seizure frequency per month during treatment in addition to improved global functioning, reduction in depression and anxiety, and improved quality of life. In another study, Goldstein et al. (2010) studied 66 patients with PNES in a four-month randomized controlled trial. They found that the CBT group was more likely to be seizure free for three months following CBT; however, there was no change in their mood or employment status. Overall, the researchers found that CBT was more effective than standard medical care (SMC) in reducing seizure frequency in PNES patients. Lastly, Rusch et al. (2001) used CBT with exposure therapy to treat a subgroup of PNES patients who were experiencing anxiety attacks which were mimicking PNES. They focused on differentiating their feelings of panic from their somatic symptoms as well as intentional exposure to situations which caused them anxiety.

Psychodynamic Therapy

Psychodynamic therapy (PDT) has also been used to treat PNES. Russell et al. (2016) described that the rationale for using PDT to treat PNES is based upon the assumption that a person's somatic symptoms are a result of their emotional dysregulation due to their pattern of unconscious avoidance of emotional experiences. They describe the aim of PDT is to encourage affect regulation and tolerance and thus promote self-reflection which then results in a reduction of somatic manifestations of emotional distress which are expressed as PNES. The purpose of PDT is to connect a person's PNES symptoms to interpersonal conflict and emotional experiences from the past (Gutkin et al., 2021).

There is also some notable evidence supporting the use of PDT to treat PNES. Gutkin et al. (2021) reviewed seven studies using PDT with PNES and concluded that PDT provided moderate improvement in seizure frequency as well as some improvements to quality of life and mental health. However, the authors did admit that the studies were in general low quality and there is a need for higher quality studies on this topic. In another study, Russel et al. (2016) studied 28 patients with PNES over nine years who had an average of 3.6 sessions of intensive short-term dynamic (ISTD) psychotherapy and showed significant reduction in healthcare costs as well as reduced long-term symptoms and interpersonal problems. ISTD is a short-term psychodynamic approach which has proven to have long term reduction of symptoms which thus reduced healthcare costs and physician visits (Russel et al., 2016). Russel et al. indicated that ISTDP was used to build affect tolerance, anxiety regulation and emotional insights. Despite the small number of participants in this study, PDT appears to have some benefits in treating PNES.

Psychoeducation

Individuals with PNES are often difficult to engage in treatment. Therefore, carefully planned psychoeducation is required since understanding PNES as a psychological condition can help patients engage willingly in psychotherapy (Dickinson et al., 2011). Therefore, if not done with consideration, patients may not accept the diagnosis, which could result in them refusing any treatment options (Demirci & Sagaltici, 2021). Kelly and Benadis (2005) highlighted how when the diagnosis is explained thoughtfully and carefully, some people's seizures stop altogether, which they acknowledge is surprising. Psychoeducation can also help in defining medical terms for people that may seem scary or overwhelming such as *dissociation* or *conversion* (Zaroff et al., 2004). Hansen et al. (2020) recommend using validating explanations such as that PNES is "a problem with the software of the brain rather than the hardware" (p. 685). The used of psychoeducation to educate and increase a client's awareness of this diagnosis can help in their symptom severity and wiliness to engage in counselling.

Group Therapy

Group therapy has been found to give people with PNES comfort in knowing they are not alone living with the challenges of PNES. This can help normalize the struggles of living with PNES, increase social connections and provide hope (Zaroff et al., 2004). Barry et al. (2008) used psychodynamic group therapy with a focus on interpersonal issues. This study resulted in decreased seizure frequency, improved symptoms of depression and increases in overall daily life functioning. Zaroff et al. (2004) used group therapy for 10 sessions with 10 PNES patients with a focus on psychoeducation and emotionally based coping strategies. Despite the small sample size, this study resulted in improved emotional coping techniques as well as a decrease in PTSD and dissociative symptoms and an overall trend toward improved quality of life. The results of several studies support the utility of group therapy to help normalize the diagnosis, provide a nonconfrontational space, as well as increase client's social support network.

EMDR

There is emerging research which incorporates EMDR in the treatment of PNES. EMDR is a proven approach used to treat PTSD with recent evidence for its treatment in treating somatic symptoms as well as PNES (Cope et al., 2018). The rationale for using this approach is based upon the high prevalence of a trauma history in PNES patients, in which EMDR has proven effective (Fiszman et al., 2004). The premise for using EMDR to treat PNES is explained by Cope et al. (2018) as addressing the psychological expressions of distress from a client's traumatic memories which may show up somatically, in the form of a PNES episode.

There is significant evidence which points to the effectiveness of using EMDR to treat PNES. For example, EMDR has been used to treat PNES clients with comorbid trauma and dissociative symptoms, with resultant reduction of seizures for more than 12 months (Kelly & Benadis, 2007). Similarly, Cope et al. (2018) found that 80% of adult patients with PTSD with co-occurring PNES were successfully treated

with EMDR. Demirci and Sagaltici (2021) used EMDR to treat youth for PNES with improved PNES symptomology. The treatment sessions in this study focused on key interventions such as: building the therapeutic alliance, psychoeducation, relaxation techniques, desensitization, and reprocessing of traumatic memories, as well as body sensation scan techniques. Despite the benefits of EMDR to treat PNESS, some researchers disagree that eye movements are necessary to reprocess the traumatic memories, but rather the key process being dual attention to tactile or auditory stimuli (Cope et al., 2018). Nonetheless, using EMDR to address how underlying trauma may be showing up somatically is a valid approach.

Acceptance and Commitment Therapy (ACT)

ACT is a third wave therapeutic approach that uses acceptance and awareness to evoke behavioural changes, by making values-based behaviour changes (Barret-Naylor et al., 2018). In addition to this, ACT also has a focus on mindfulness, compassion, and living in the moment (Harris, 2004). The goal of ACT is to help clients live a rich, meaningful, and vibrant life, which is referred to as the concept of *workability*. Harris (2006) describes workability as "Is what you're doing working to give you the sort of life you want, in the long term?" if the answer is yes, then the behaviour or thought is described as workable (p. 23). ACT also assumes that psychological suffering is a normal process and inevitable in all humans (Harris, 2004). Furthermore, A key theory of ACT is *relational frame theory* which is a behavioural view of language that suggests people respond to their world through language rather than the experience of the present moment (Hayes, 2019). This focus on language and words is important for people with PNES who frequently navigate stigmatizing language and medicalized terminology.

ACT is based upon a client developing *psychological flexibility* which include six core principles: cognitive defusion, acceptance, contact with the present moment, the observing self, values, and committed action (Harris, 2006). Cognitive defusion is a key component of ACT that separates it from CBT and is based upon the idea that when we get caught up in our thoughts, they become fused to our

cognitive process which makes them feel very real (Harris, 2006). Therefore, cognitive defusion creates space between the fused idea or thought which reduces the impact it has on individuals (Harris, 2006). In contrast to CBT, the goal of cognitive defusion is not to disrupt the unhelpful thought but rather to observe it non-judgementally. The goal of cognitive defusion would be to create space from the problematic thought and notice it for what it is as "just bits of language passing through" (Harris, 2006, p. 7). The second component of psychological flexibility referred to as acceptance, involves allowing unhelpful feelings, emotions, and experiences to come and go without a struggle. This may involve a client noticing their feelings of anxiety and sitting with this feeling and observing how it feels in the body without trying to get rid of the feeling (Harris, 2006). The next element, contact with the present moment, involves being in the moment and not dwelling on the past or future. This would involve using mindfulness techniques to be in the moment such as focusing on all five senses: taste, smell, sensation, noise, and movements (Harris, 2006). The observing self element of psychological flexibility is the ability to separate and view one's thoughts and emotions from a separate self, almost as if a fly-on-the-wall. Harris (2006) describes the benefit of this perspective as realizing that "you are not your thoughts, feelings, memories, urges, sensations, images, roles or physical body" (p. 7). The next element of psychological flexibility, values, involves clarifying what is most important and meaningful to a client, what type of person they would like to be and what they would want to stand for. The last element of psychological flexibility, committed action, involves goal setting, making decisions and taking action-based upon the values the client identified as being most important to then (Harris, 2006).

Unlike CBT, the goal of ACT is not symptom reduction, therefore seizure reduction is not the goal of using ACT to treat PNES. ACT differs from a CBT approach in that it does not aim to change the undesired behaviour, but rather uses acceptance and awareness techniques in order to distance oneself from the problem (Barret-Naylor et al., 2018). Harris (2004) explained how trying to eliminate symptoms can cause great psychological distress. Therefore, the goal of using ACT to treat PNES would

be to learn to accept and live with PNES in a healthy and adaptive way. This would have a trickle-down effect of reducing the distressing PNES symptoms as a by-product. Therefore, the goal of using ACT to treat PNES is to live a meaningful and high quality of life, despite this diagnosis. The following paragraphs will describe the rationale, evidence, and applicability of using ACT to treat PNES.

Rationale for Using ACT to Treat PNES. The theory of ACT has promising applications for PNES treatment. For starters, the key processes of ACT which thought to be effective for PNES clients are increasing psychological flexibility and decreasing experiential avoidance (Cope et al., 2017). The focus on avoidance could be beneficial for PNES treatment since it is considered a form of dissociation - a key process in PNES. Furthermore, the authors also explain how ACT can be beneficial by increasing one's connection to their internal experience such as bodily sensations, thoughts, and emotions.

ACT also aims to create an individualized approach to treating each client and even collaborating with the therapist in treatment (Harris, 2004). ACT is a therapeutic modality which is similar to CBT, with the addition of a focus on mindfulness and values (Cope et al., 2017). Even though CBT is currently considered the most effective treatment for PNES, it is not effective for everyone and this is thought to be due to the complexity and heterogeneity of the population (Cope et al., 2017). In fact, emerging research has demonstrated ACT to be more beneficial than CBT in treating other psychological conditions such as anxiety, addictions, and somatic symptoms (A-Tjak et al., 2014). It could also be that CBT is currently the most effective treatment simply because there has not been sufficient research on the topic to support any alternatives (Cope et al., 2017).

Evidence for Using ACT to Treat PNES. There is currently no robust research on treating specifically PNES with ACT, with the exception of one study found with an extensive literature search. Despite this noticeable gap in knowledge, there have been numerous studies evaluating the efficacy of ACT in other conditions such as chronic pain, depression, psychosis, and epilepsy (Cope et al., 2017). It has also been proven useful in the treatment of PTSD, anxiety, obsessive compulsive disorder (OCD) and

workplace stress (Hayes et al., 2006; Twohig et al., 2006). Moreover, there is research by Ruiz (2012) comparing CBT to ACT to treat range of psychological and physical conditions such as OCD, chronic pain, and cancer. There is also research suggesting its benefits in treating addictions and somatic health problems (A-Tjak et al., 2014). ACT's effectiveness with other psychiatric conditions provide reason to believe its potential benefits in treating PNES warrants further exploration.

Applicability of Using ACT. With an extensive online search for scholarly studies using specifically ACT to treat PNES, only one such journal article was found. In this study, Barret-Naylor et al. (2018) researched the use of ACT on six people with PNES over the course of six weeks and found reliable improvements in quality of life, psychological health, and reduction in seizure frequency for most participants. This study focused on the key process of ACT of increasing the participant's psychological flexibility. The authors recommend that reducing experiential avoidance, increasing acceptance of adverse sensations, and improving cognitive and bodily awareness can contribute to reducing PNES frequency. Another study by Baslet and Hill (2011) did not use ACT specifically but used elements of CBT with mindfulness interventions to treat a PNES case study. This study describes a woman who underwent mindfulness interventions while focusing on emotional expression and experiential avoidance to address PNES symptoms, anxiety, and depression. She was experiencing increased PNES seizures as a result of personal life stressors which manifested as left-sided paralysis, psychogenic bilateral tremors, and dissociative amnesia. The use of mindfulness-based interventions was found to significantly reduce her PNES symptoms. With such a lack of scholarly research using ACT to treat PNES, applications of ACT's usefulness in treating other conditions warrants exploration.

Even though there is limited research using ACT to treat PNES specifically, there is a wealth of studies using ACT to treat other psychological and somatic conditions in which relevant approaches and interventions could be used to also treat PNES. In one such study, Dahl et al. (2004) used ACT to treat Swedish individuals who suffered from frequent workplace absences due to chronic pain. The

researchers focused on the idea of experiential avoidance since the individuals in the study were using workplace avoidance to cope with their chronic pain. This study used traditional exposure therapy while also focusing on values and defusing inflexible cognitions. In this study, there was no attempt to eliminate the participants negative feelings associated with chronic pain, but rather acceptance and mindfulness was used to acknowledge the pain to create workability in the participants life. Along these lines, Twohig et al. (2006) studied individuals with obsessive skin picking and found that it was a function of people with high levels of emotional and experiential avoidance. Using an ACT approach, the participants attempt to control the skin picking are thought to exacerbate the symptoms rather then alleviate it, therefore, acceptance, values, and cognitive defusion were used to alleviate the symptoms. By investigating the usefulness of ACT in treating other conditions, there is promising transferable applications for the treatment of PNES.

Somatic-Based Therapies

Somatic-based therapies are modalities typically used to treat PTSD and trauma in the body and are an emerging field which is filling a gap in trauma treatment (KuhfuB et al., 2021). While it is true that not all people with PNES have experienced trauma, given the high documented percentage of 85-100% it would still be useful to consider the benefits of this approach (Brown & Reuber, 2016). Somatic therapies are considered “bottom up” approaches to healing stress and trauma in the body by focusing on the subcortical structures of the brain such as the limbic system and brain stem, which work to change the body’s response to stressful experiencing (Kuhfuß et al., 2021, p. 3). By using the body in therapy, it works to change the body’s physiological and emotional responses to stressful events (Kuhfuß et al., 2021). Somatic-based therapies are a useful approach for people who struggle with cognitive abilities or have other psychological comorbidities, since this group of people are often resistant to CBT treatment (KuhfuB et al., 2021). Somatic-based therapies such as Pat Odgen’s (1981) sensorimotor (SP) therapy and Peter Levine’s (1997) somatic experiencing (SE) and will first be

described, then explored in terms of the rationale, evidence, and applicability for their potential efficacy to treat PNES.

Sensorimotor Psychotherapy. Sensorimotor psychotherapy (SP) was founded by Pat Odgen in 1981 as a treatment method for those who struggle with trauma, attachment failures, mind/body connection and self-regulation (Masero, 2017). SP incorporates ideas of neuroscience and sensory integration into its treatment (Fisher, 2019). Ogden (2021) posits that people need to involve the body when healing trauma since ultimately, individuals develop patterns in the body that need to be resolved somatically. Patients could try to resolve it cognitively or emotionally, but the root is in the dysregulated nervous system and defensive systems in the body (Ogden, 2021).

SP uses several key concepts such as regulating a person's level of arousal into a *window of tolerance*, which describes a sinusoidal graph of regulated autonomic arousal (Corrigan et al., 2010). Fisher (2019) described this concept in layman's terms as the "increased capacity for both positive and negative stimuli and more ability to recover easily from states of distress" (p. 163). In SP, the goal is to help clients increase their window of tolerance by learning to regulate their distress and self regulate in a more adaptive way. Ogden (2021) explains how SP incorporates John Bowlby's famous theory of attachment. She explains how the client's attachment style shows up somatically, and interventions in SP encourage secure attachment. Awareness of the client's attachment style can also contribute to the therapeutic alliance by facilitating safety and security in the therapist-client relationship through affect regulation (Schore, 2014). Similar to ACT, SP encourages mindful awareness, curiosity and reducing feelings of judgment and self-blame (Fisher, 2019). SP does not aim to get rid of the unwanted behaviours, such as non-epileptic seizures, but encourages the use of mindful awareness to observe nonjudgmentally the physical experience (Fisher, 2019).

Somatic Experiencing (SE). Somatic Experiencing (SE) is another body-oriented approach pioneered by Peter Levine in 1997, which uses the body's response to traumatic events by directing

client's attentions to interoceptive, kinesthetic, and proprioceptive sensations (Kuhfuß et al., 2021). Levine (1997) explains that when people are unable to complete the stress cycle it can show up as chronic somatic symptoms and emotional dysregulation. Payne et al. (2015) described how unlike CBT, which focuses on people's conscious cognitions and emotions, SE aims to direct people's attention to their bodily sensations which may include both visceral or interoception as well as musculoskeletal or proprioception. The authors also described how it is also important to note that SE differs from exposure therapy in that it approaches a person's traumatic memories in a gentle and indirect way. The result of these interventions is a release or discharge of trauma and stress in the body which presents as excess autonomic arousal. Payne et al. indicated that SE incorporates many of the ideas of other traditional practices which have a focus on internal awareness such as yoga, T'ai Chi as well as mindfulness mediation techniques. SE helps clients to re-experience the bodily sensations associated with trauma in a safe and supported environment in order to finish their stress cycle (Payne et al., 2015).

There are several key concepts of SE which have applicability to treating PNES. One such concept in treating trauma with SE is referred to as resourcing, which is described by Payne et al. (2015) as putting a client in touch with feelings of safety and comfort so the work can begin to regulate their nervous system. The counsellor accomplishes this through the use of eye contact, voice and prosody of speech, body language and by encouraging positive physical sensations through their physical environment. Another important concept of SE is called titration, which Payne et al. explains is the method of introducing a traumatic memory "drop by drop" so not to overload an individual with flooded traumatic memories but to rather carefully introducing a small manageable memory of the traumatic event (Payne et al., 2015). SE also uses gentle discharge to release troublesome emotions without over activating the sympathetic nervous system (Payne et al., 2015). This gentle and careful balance between "charge/activation and discharge/deactivation" is referred to a pendulation and aims to restore balance between the sympathetic and parasympathetic nervous system (Payne et al., 2015, p. 8).

Rationale for Using Somatic-Based Therapies to Treat PNES. The rationale for using somatic-based therapies to treat PNES is rooted in the biopsychosocial theoretical framework guiding this capstone. This framework recognizes PNES as a condition involving psychological and physiological processes, therefore both need to be addressed in treatment with the addition of social factors. This approach would aim to build a mind-body connection and somatic awareness, which can then be used to regulate the body's dysregulated autonomic system (Myers et. al, 2021).

A trauma informed lens also guides this capstone. Somatic based therapies are proven modalities to treat clients who have experiences with trauma, by also using a trauma-informed approach. Fisher (2019) described when a person is repeatedly exposed to trauma and threat, this results in a distressed state or hyperarousal, and the body responds with a dysregulated nervous system. She also explained how after the sympathetic responses are activated into the fight-or-flight stress responses the parasympathetic system then works to inhibit this response which results in the opposite response of exhaustion, numbing and decreased heart rate. Payne et al. (2015) asserted that biologically speaking, when a person feels threatened and dysregulated emotionally, they respond somatically in a way to defend themselves. This research demonstrates how animals in the wild respond to threat by having "involuntary movements, changes in breathing patterns, yawning, shaking, and trembling, release or discharge the intense biological arousal" (Payne et al., p. 14). This description of animals feeling threatened in the wild, sounds remarkably similar to the clinical presentation of a person experiencing PNES, this being changes in motor, sensory and behavioural systems as well as changes in awareness and consciousness (APA, 2013).

Evidence for using Somatic Therapies to Treat PNES. There are no specific studies found using SE or SP to treat PNES in an extensive online search for peer reviewed literature. Nonetheless, there were two studies found using non-specific body-based therapies to treat PNES.

Applicability of using Somatic Therapies to Treat PNES. Senf-Beckenback et al. (2021) studied 53

people with PNES who were treated with a body-focused group therapy program or a guided self-help group. The study showed that the body-focused group therapy had superior results in reducing seizure severity six months later. This specific body-focused therapy was not SP or SE but rather a variation of CBT which had an additional focus on bodily symptom awareness and dissociation. Similarly, Rusch et al. (2001) studied 26 individuals with PNES and found that focusing therapy on increasing connections to somatic experiences helped to reduce seizure frequency. The study also found that a large group of people with PNES experienced longstanding patterns of somatization with patterns of frequently seeking medical attention. This study helped to identify stressors which were triggering for the somatic symptoms such as employment challenges, family crises or other medical issues. Rusch et al. used a focus on problem solving and recognizing the link between the stressor and the somatic response with less focus on the seizure event in itself. Despite the limited number of somatic based therapies found treating PNES specifically, these limited finding show potential for its future effectiveness for PNES clients.

There are also numerous studies done using SE and SP to treat trauma and PTSD, which have a well documented connection to PNES (Brown & Reuber, 2016). For example, Gen-Cos et al. (2016) used SP in the treatment of complex PTSD (CPTSD). The focus of the treatment was on body awareness, psychoeducation, affect regulation, and skills for regulating autonomic arousal adaptive responses (Fisher, 2019). Gen-Cos et al. described many of the symptoms of CPTSD as the same as PNES, such as dissociation, hypervigilance, body numbing, hyper arousal, avoidance, anxiety, alexithymia and even some impaired motor responses. This study found decreased depression and PTSD symptoms as well as an overall increase in well-being. Even though this study was not targeted at PNES, one cannot ignore the potential applications.

Despite the complete lack of specific research using SP or SE to treat PNES, there is potential for benefits to treat this population by focusing on somatic manifestations of stress and trauma while also

encouraging affect regulation techniques. Fisher (2019) described how body-based therapies help to develop emotional-regulation techniques, which is also a known vulnerability trait of PNES. Even though there is essentially no specific research using somatic-based therapies to treat PNES, it does not mean that it would not be an effective approach. It is a relatively new concept to treat a psychological condition by using a somatic based therapy, which warrants further research as it pertains to PNES.

Chapter Two Conclusion and Synthesis

This literature review highlighted many key themes existing in the current research into PNES. A detailed description was provided for PNES by highlighting its clinical presentation, diagnosis, impact on daily life, outcome, vulnerability traits, prevalence, current treatments, and cultural considerations. This was followed by an in-depth exploration of the stigma this population experiences in the use of the term itself, diagnosis, and in healthcare as well as in society. Lastly, a review of the most currently used counselling modalities was provided with key standouts being the importance of a person-centered approach, psychoeducation, validating, exploring cognitive and behavioural responses to stress, and maintaining a trauma-informed lens. A detailed exploration of ACT was provided with many key takeaways such as incorporating acceptance, awareness, mindfulness, nonjudgement, and psychological flexibility. Despite the lack of research on using somatic-based therapies, there are valid concepts based upon neuroscience which could be applied to treating PNES patients such as interventions aimed at regulating the autonomic nervous system, self-regulating techniques, and somatic awareness. The following chapter will provide an overview of best clinical practices for treating PNES clients, based upon these key findings and takeaways from this chapter.

Chapter 3: Discussion and Application

This final chapter will provide a discussion of PNES while also revisiting the main purposes of this capstone paper. As such, the aim of this final chapter is also practical, in that it will provide an overview of best practices to treat this client population based upon the main themes which emerged from the previous chapter's literature review. This will be accomplished by proposing guidelines for a psychoeducational workshop for counsellors who wish to gain insight and recommendations to work with this unique client population. An itinerary for the suggested workshop can be found in Appendix A.

Summary and Synthesis

The intentionality of this capstone paper is four-fold. The first being to provide a detailed description of PNES. This includes a description of the challenges in arriving at this diagnosis and the impact on a person's life, the vulnerability traits which make a person more susceptible to having this condition as well as cultural considerations. The second purpose is to reduce the stigma associated with this diagnosis by adding to the understanding of this poorly understood and complicated condition, and thus reducing the knowledge gap. The third purpose of this capstone paper is to provide a brief overview of the current psychotherapeutic approaches to treat this condition with a focus on ACT and somatic based therapies. Fourthly, as a result of synthesizing the clinical research on this topic, this final chapter will provide recommendations to work with this client population in a counselling setting. This will be accomplished by providing a suggested itinerary for a psychoeducational workshop that counsellors can take if they are wishing to learn more about working with this population.

Theoretical Framework used in this Capstone Paper

Trauma Informed Approach. Based upon the literature review in the previous chapter, there are a multitude of well documented vulnerability traits that people with PNES may have. One of the most commonly reported being the lived experience of trauma, and in various forms. Given this population's high incidence of trauma, it is essential to use a trauma-informed approach when treating this

population. This means that counsellors need to consider the whole individual when treating them by recognizing the effects trauma has had on their physical and mental health, behaviour as well as their ability to engage in counselling. Therefore, counsellors have an ethical duty to follow the six guiding principles of trauma-informed care as recommended by SAMHSA (2014) which include: (1) creating safety, (2) trustworthiness and transparency, (3) peer support, (4) collaboration and mutuality, (5) empowerment, voice, and choice, and (6) cultural, historical and gender issues. These key concepts will be used when treating clients with PNES.

Biopsychosocialspiritual Approach. In addition to trauma, other known vulnerability traits of PNES include dissociation tendencies, challenges with emotional processing, anxiety, other medical comorbidities, and being female as well as family and social stressors. Given these commonly encountered traits of people with PNES, the current research highlights the importance of using the philosophical lens of a biopsychosocialspiritual approach to guide clinical practice. This approach takes into account the interconnection between the mind, body, and social factors contributing to this condition. Whereas traditional western medicine uses a biomedical model of viewing health, psychology prefers to view health through the biopsychosocial model in which a person's physical health is connected to their psychological and mental health which is also influenced by societal factors.

As an addition to this biospychosocial approach, one could add the influence of a person's spirituality on their health, thus resulting in a *biopsychosocialspiritual* approach. At this point it is important to define spirituality as "one's religious beliefs and practices as well as one's sense of purpose and meaning in life" (Gale, 2022, p. 1). This is a holistic approach that takes into consideration the interplay between a person's biological, psychological, social, *and* spiritual elements in their life. Even if a person does not identify with organized religion, or perhaps considers themselves an atheist, they may identify with another higher purpose and meaning to their life. Therefore, examining the existential

question of “why me” and what meaning they can draw from their experiences with PNES is also important to consider.

Stigma and PNES

Stigma is another frequently recurring theme which stood out when researching the topic of PNES. In fact, several prominent experiences of stigma emerged during the research process of this capstone paper. The first being the stigma associated with the term PNES itself. The conundrum of what to label this condition using the least stigmatizing language possible is hotly debated by researchers with the top contenders being PNES, functional seizures (FS), and nonepileptic seizures (NES) - just to name a few. It was clear from the scholarly literature that language matters, and there are trickle-down effects from the label used in terms of available social supports, healthcare policy and funding available to patients. The second source of stigma identified was the stigma associated with having the label and diagnosis of PNES. This is because there is shame and stigma associated with a PNES diagnosis since it is not considered as legitimate or serious a condition as epilepsy. Because of this, a PNES diagnosis carries the stigma and negative connotations associated with a mental illness. The largest amount of stigma literature devoted to PNES with an extensive literature search was the third source: stigma from healthcare. This is the stigma a patient experiences from healthcare professionals or within the structure and policies of hospitals and healthcare providers. There were numerous firsthand accounts of PNES patients reporting healthcare workers – whether that be nurses, physicians or technologists who discounted their diagnosis, laughed behind their backs, or accused them of “faking it” (Robson & Lian, 2017, p. 8). The fourth source of stigma explored in this capstone was the experience of stigma from society. This is the stigma a person experiences when their quality-of-life changes. This could be a result of being unable to drive, unable to maintain employment, and the experience of feeling like a burden to family members or caregivers. This could also be the experience of having a PNES seizure in public and the shame and stigma that may cause for the individual.

Therapeutic Approaches and PNES

In part three of the literature review, the current scholarly research on using therapeutic approaches to treat this patient population through counselling were explored. A brief overview of the currently most used approaches, CBT, and psychoeducation were reviewed. Other interventions such as psychodynamic therapy, group therapy and EMDR were also given a brief overview. This was followed by a more thorough examination of the potential of two newer approaches, ACT, and somatic-based therapies. Despite the lack of scholarly research using these last two modalities, an in-depth exploration of the rationale, evidence, and applicability of these approaches was examined based on their use in treating other psychological and physical health conditions.

As a result of synthesizing the available research as it pertains to therapeutic approaches to treat PNES through counselling, several prevalent themes emerged. First, before counselling begins, it is important to consider ethical dilemmas such as client safety. This is a unique client population that is prone to having unexpected PNES seizures in public and so a thorough exploration of safety is vital. This would include collaborating on a safety plan in the event of a PNES seizure. Examples of questions to ask would be how they would like their counsellor to respond in the event of a PNES seizure. Should the session continue in the event of a seizure or should the session end? Are there any transportation barriers in coming to counselling or would virtual counselling be more appropriate? If the session is virtual, is there someone in the house in case of a seizure? There may need to be a plan in place if the client has a seizure during a virtual session such as having the counsellor call someone in the home where the session is taking place. Given the confidentiality of counselling sessions it is important for the client to be in a confidential space if the session is virtual (Stoll et al., 2020).

Psychoeducation is important not just in helping the client to understand their diagnosis but also in explaining the benefits of counselling. Psychoeducation is also essential for the counsellor treating the client so that they have an awareness of PNES so as not to inadvertently use stigmatizing

language and cause client harm. One challenge with this population group is a reluctance to engage in psychotherapy, and a lack of insight into their own condition (Tolchin et al., 2020). Careful psychoeducation as to the benefits of counselling by using motivational interviewing (MI) style questions can help to decrease ambivalence about counselling.

The literature review on somatic based therapies revealed several prominent themes which emerged as being helpful for working with PNES clients who have experienced trauma and also suffer from other mental health and physical medical conditions. Even though there was almost a complete lack of research using somatic based therapies to treat PNES, its potential for benefiting this client population is backed by the evidence in showing benefits to other conditions. The key challenges of emotional regulation, anxiety, disconnection from somatic sensations, lack of bodily awareness, and experiences of trauma will be addressed in the following proposed counselling best practices (Fisher, 2019; Gen-Cos et al., 2016; Rusch et al., 2001). Interventions which would be of value when counselling PNES clients are: Grounding techniques, resourcing, exploring client's attachment history and style, window of tolerance, titration, somatic awareness, and increasing bodily connections as well as learning to regulate affect and arousal (Hansen, 2016; NICABM, 2017; Schore, 2014; TherapistAid.com, 2022).

There were also many favorable uses of ACT for treating PNES. Key interventions that would be recommended for best practices when treating clients with PNES are the use of mindfulness skills, cognitive defusion, acceptance, values and committed actions as well as self-compassion (Barret-Naylor et al.; 2018; Baslet and Hill, 2011; Dahl et al.; 2004; Twohig et al., 2006). In the following applied practices section, a suggested itinerary for a psychoeducation workshop for counsellors wanting to work with this client population will be proposed, using these key ideas.

Limitations and Constraints

The main limitation of this capstone paper is the lack of scholarly research available in counselling interventions to use with people with PNES. Since this population is known to have low

adherence to psychotherapy despite its documented benefits, there was also little research into how to motivate and engage clients in psychotherapy. There was also a complete lack of research on using somatic based therapies and very scant research using ACT. Although the gold standard of psychological treatment has been CBT, there is emerging research into the vulnerability traits of PNES anxiety and other medical comorbidities, which suggest the applicability of other mindfulness-based modalities such as ACT. The vulnerability traits of trauma, dissociation, alexithymia, somatization, and struggles with emotional regulation suggest that somatic based therapies warrant research as well.

Another clear limitation of this topic is the lack of research using non-western countries and societies. With the exception of the research of Asadi-Pooya et al. (2019), the majority of the studies used for the capstone were from western countries. Further cultural studies in other parts of the world would be interesting to study and given the high prevalence of women (75%) with PNES, it would also be interesting to study PNES with a feminist perspective, taking into account systems of oppression that women face especially in non-western cultures where there may be stark differences in gender roles and expectations. The findings from the cross-cultural research by Asadi-Pooya et al. (2019) were that women with PNES in Iran, for example, experienced greater clinical symptoms of PNES compared to women from western countries. The researcher's considered that women are historically subjected to significant cultural and societal stress, and a lack of emotional expression. Such findings warrant further investigation.

In thinking about culture and PNES, there is also a marked absence of research on the cultural manifestations of stigma and PNES. Along these lines, there is also a lack of research on the structural and societal impacts of stigma and PNES. In fact, the topic of stigma and PNES is itself so multifaceted that it could easily warrant another capstone project. In particular, there is a lack of research on the impact of PNES from the patient's point of view, and the manifestations of stigma that these individuals experience from being given this diagnosis, and their experience in healthcare and in society. There is a

plethora of research on experiences of mental illness stigma. However, there is a lack of scholarly literature on specifically stigma and PNES. It would be remiss not to point out that there are notable recent studies describing the experience of stigma and shame from the patient's point of view by Robson and Lian (2017), Myers et al. (2022) and Annadale et al. (2022). This experience of stigma is also related to the lack of agreement on what term and label this condition should be given.

Along the lines of stigma, there was also a lack of scholarly research into the effects that stigma of this diagnosis has on the social structures of society. By this, I am referring to the trickle-down effects of public support described by Fox et al. (2018) in terms of healthcare funding and policy support. Fox et al. also indicate that stigma is "socially constructed and reinforced," which lends itself to thinking about how the experience of stigma and PNES is socially constructed (p. 5). There is also a lack of research into the intersectional experience of having stigma if the person also has additional locations of marginalization in terms of race, socioeconomic status, gender, or if they live with other medical comorbidities or disabilities.

Best Practices for Counselling PNES Clients

Counselling clients with PNES is not a one-size-fits all approach due to the complexity of this condition. Rather, a counselling treatment plan should consider the client's presenting concerns, medical comorbidities, experiences of trauma, motivation for change, and psychosocial factors. With this in mind, the following recommendations for future clinical practice when treating PNES clients in counselling are meant to be personalized and tailored to each individual rather than a manualized approach. By this, I mean that what may work for one client may not be useful to another client. It is also important that each client feels like they are in the driver's seat of therapy, and having open discussions about what works for each individual and where they would prefer to focus could also add to the therapeutic alliance and feeling of agency. The following is a proposed itinerary for a one-day

psychoeducational workshop for counsellors outlining recommended best practices when counselling clients with PNES. The suggested agenda can be found at the end of this capstone paper in Appendix A.

The workshop will begin with introductions and an overview of the objectives for the day. This will be followed by providing a description of PNES in terms of its clinical presentation, a brief description of how PNES is diagnosed as well as a description of the impact of PNES on daily life. Next will be an overview of the vulnerability traits identified for PNES including a description of the high prevalence of patients who have experienced trauma, dissociation tendencies, challenges with emotional processing, anxiety, other medical comorbidities, being female, and family and social stressors.

Following this there will be a discussion surrounding where to start when counselling this unique population such as using a person-centered and trauma informed approach. This will also include the importance of discussing a safety plan with the client prior to the first session to prepare for the possible event of a PNES seizure. Having a safety plan in place will ensure the client is safe in the event of a seizure, as well as provide reassurance that safety precautions are in place.

Following a brief break, the importance of assessing the client's motivation for counseling will be described. Given the PNES population's general ambivalence about the benefits of psychotherapy and often lack of insight into their own condition, psychoeducation as to the benefits of counselling will be emphasized.

The following hour of the workshop will be devoted to the substantial topic of stigma and PNES. This is an important issue to be aware of when treating clients with PNES due to its impact on daily functioning and life. The four themes described will be firstly the stigma associated with the term PNES itself and with other commonly used terms. This will be followed by an overview of the considerable stigma experienced by PNES patients in healthcare. Lastly will be a description of the stigma experience by people living with this diagnosis in their daily lives and by society.

Following a lunch break, an overview of the rationale and evidence for the applicability for using somatic-based therapies will be provided. This will be followed by a description of suggested interventions for people with PNES such as grounding techniques, resourcing, exploring attachment styles, window of tolerance, titration, pendulation and somatic awareness. While specific interventions are provided, this is meant to be more of a jumping off point for counsellors to use their own research, experience, and creativity in selecting appropriate interventions.

Subsequently, an overview of the rationale and evidence for using ACT to treat PNES will be described. This will be followed by a description of suggested interventions with a focus on key tenets of ACT. These include cognitive defusion, acceptance, mindfulness skills, values and committed actions and self-compassion. As with the previously mentioned somatic-based interventions, the suggested ACT interventions are also meant as a starting point for counsellors.

Next will be a brief overview of other notable and commonly used therapeutic modalities to treat PNES. This includes CBT, psychodynamic therapy, group therapy and EMDR. Lastly, the workshop will conclude with a final discussion as well as closing remarks.

Reflections on Personal Learning

This has been an immensely rewarding topic to study and do a deep dive into since this is a something I have seen on a weekly basis for the past 15 years in my career as an EEG technologist. My own understanding and empathy for this condition has grown and so has my desire to work with this population in my future work as a counsellor.

One curiosity and tension I have experienced during the writing of this capstone is that I have not yet counselled a client who has PNES. Because of this, I wonder if some of my proposed approaches in treating this patient population may change once I have the lived experience in counselling individuals with PNES. It is also in the forefront of my mind that the complexities of the safety risks in treating this

group have to be taken seriously and this is undoubtedly a significant barrier this population faces in finding a counsellor to treat them.

Conclusions

One intention of researching PNES for this capstone paper is to inform my own future practice as a clinical counsellor. There is a clear gap in psychiatric treatments for this patient population and so the hope for this capstone is to inform and direct clinicians in the best practices when working with PNES clients. It is important for clinicians to be informed about the presentation and challenges with diagnosis of this condition as well as having an awareness of the numerous forms of stigma that could be experienced by the client. In the proposed psychoeducational workshop itinerary (see Appendix), the key elements of safety planning, psychoeducation, and motivation for treatment were outlined. The best practices which are recommended for counselling treatment include key interventions taken from somatic-based therapy and ACT while also giving a review of the currently most used therapeutic modalities.

In researching this capstone paper, I believe a personalized approach to treating this population should be taken based upon the unique clinical presentation of each individual and what their specific challenges are. It is also important to recognize that in many cases seizure reduction may not be possible and therefore seizure reduction should not be the measure of outcome, rather, quality of life and the ability to continue to live a meaningful life should be emphasized.

One final reflection is that this capstone project is to help give direction to PNES patients who do not know where to turn following their diagnosis, which seems to linger between the two vast worlds of psychiatry and neurology. Looking into the future, the research findings from this capstone project could also have applications for other medical and psychiatric conditions which are somatic in nature or which may have similar symptoms such as challenges with emotional regulation, anxiety, and trauma or

dissociation. Furthermore, opening the discussion surrounding stigma and how we treat patients in the medical system based upon their diagnosis also feels like a welcome change.

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Appendix A

Psychoeducational Workshop for Counsellors

This appendix contains a suggested itinerary for a psychoeducational workshop for counsellors when working with clients with PNES.

Table A1

Psychoeducational Workshop for Counsellors: Recommended Best Practices when Working with Clients with Psychogenic Non-Epileptic Seizures

9:00-9:15	**Introductions and Overview of Workshop** **Objectives of Workshop** 1. Provide a description of PNES 2. Where to start when counselling a person with PNES? 3. Motivation for counselling 4. Stigma and PNES 5. Somatic approaches 6. ACT approaches 7. Other notable therapeutic approaches

9:15-9:45	**What are Psychogenic Non-Epileptic Seizures?**
	
	• An overview of clinical presentation
	• A brief description of how this condition is diagnosed and the numerous challenges involved in arriving at a diagnosis.
	  ○ Question: What is the difference between PNES and epilepsy?
	• The impact of PNES on a person's daily life as well as the impact on their loved ones.
	• An overview of the vulnerability traits according to recent research
	  ○ Trauma
	  ○ Dissociation Tendencies
	  ○ Challenges with Emotional Processing
	  ○ Anxiety
	  ○ Other Medical Comorbidities
	  ○ Females
	  ○ Family and Social Stressors

	Where to start when counselling a person with PNES? • Create a person-centered and trauma informed space for the client **Safety Discussion Prior to the First Session:**

9:45-10:30	• How often is the client having seizures and is there possibility they may have one in session?
	• Collaborate on a safety plan in the event of a seizure during session.
	• Agree beforehand what steps need to be taken if a seizure occurs
	  ○ Do they want to end the session or take a break and resume?
	  ○ Would they feel more comfortable with the session being virtual?
	  ○ Are there logistic obstacles in reaching a session in person if they cannot drive?

9:45-10:00	**Coffee Break**

10:00-10:30	**Assess Motivation for Counselling**
	
	• Psychoeducation on benefits of counselling to treat PNES
	• Assess motivation for counselling
	• If client is ambivalent about counselling use MI questioning to increase motivation for counselling
	  ○ Open ended questions
	  ○ Validating and highlighting strengths
	  ○ Reflective listening
	  ○ Focus on ability, desire and change statements
	  ○ Encourage client sense of agency
	• Past experiences and perceptions with counselling
	• Discussion of client's possible experiences with stigma

10:30-11:30	**Topic: Stigma and PNES** A brief description of the stigma this population face: • The terms and labelling of this condition • Healthcare • Stigma with living with this diagnosis • Society
11:30-11:45	**Collaborate with Client on Goals for Counselling** • Start with small achievable goals • Is reducing seizure frequency the goal? Or is increasing the ability to live a meaningful life with seizures the goal?
11:45-12:15	**Lunch Break**

12:15-1:30	**Somatic-Based Therapies** • Overview of rationale and evidence for their applicability with PNES **Suggested Interventions:** *Note: sample interventions are given and are meant to be a starting point.* Grounding Techniques • 5-4-3-2-1- technique (TherapistAid.com, 2022) • Body Awareness (TherapistAid.com, 2022) Resourcing • Imagine a safe and calming space and imagine being there and how that feels (Hansen, 2016). Attachments • Exploring client's attachment style and history • Encouraging attachment through the therapeutic alliance by encouraging safety through right brain communications such as matching prosody of speech, facial expressions, and gestures (Schore, 2014) Window of Tolerance (NICABM, 2017) • Interventions to encourage self-regulation • Emotional awareness • Breathing techniques • Movement to learn to self-regulate Titration • Slow down the difficult emotions and sensations in the body and then separate them out one bit at a time (Hanson, 2016). Pendulation • Think of a difficult emotion which may cause activation such as terror, anger or fear and sit with that deeply for a few moments. Then direct attention to a positive feeling of safety in the body. Go back and forth between the positive and negative to build the ability to sit with the negative emotions (Hanson, 2016) Somatic Awareness • Body scan Script (TherapistAid.com, 2022) • Contact/Self-Holding Exercise (Hanson, 2016) • Tracking/Felt Sense (Hanson, 2016) • Learning to direct attention to internal states • Awareness of spatial orientation of the body • Awareness of movements of the body

	• Dual Awareness. Helping clients to differentiate past and present: "When you remember that experience then, what happens here and now inside you?"
1:30 - 1:45	**Coffee Break**
1:45-2:45	**Elements of ACT to use with PNES** • Overview of rationale and evidence for its applicability with PNES *The following suggested exercises are taken from ACT Made Simple by Russ Harris (2019)* Cognitive defusion • Observing unhelpful thoughts non-judgmentally • "The Leaves on a Stream Exercise" (p. 174) Defusing inflexible cognitions • Hands as thoughts and feelings exercise (p. 21-22) Acceptance • Acceptance of adverse sensations • Bodily awareness Mindfulness Skills to connect with the present moment • Dropping Anchor mindfulness skill (p. 112) o **A** - Acknowledge your inner experience o **C** - Come back to your body o **E** - Engage with the world • RAIN mindfulness exercise (Brach, 2012) This is an acronym for a 4-step process o **R** – recognize (your experience) o **A** – allow (it to be as it is) o **I** – investigate (with curiosity) o **N** – non-identification (we are more than our thoughts and feelings) Values and Committed Actions • Naming client's core values • Making committed actions base upon values Self-Compassion • The two friend's metaphor (p. 203)

2:45-3:00	**Brief overview of other notable therapeutic modalities when working with PNES clients** • Cognitive Behavioural Therapy • Psychodynamic Therapy • Group Therapy • EMDR
3:15-4:00	**Final Discussion and Closing Remarks**