Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures

by
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Declaration

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Abstract

Psychogenic Non-Epileptic Seizures (PNES) is a mental health condition through which seizures are somatically manifested as a result of psychological distress. Owing to PNES, patients presenting with seizures which are of a psychological, rather than a physiological origin, are often perceived to be unpredictable and less deserving of care by healthcare providers (HCPs). This is mainly related to the general attitude held within the wider healthcare system that PNES should not be regarded as a clinical entity, as well as HCPs' relative limited knowledge about the condition. As a result, PNES patients face a high degree of stigma from HCPs, which thus has a negative effect on their diagnostic and treatment procedures.

Moreover, there is limited awareness about stigma towards people with PNES. The majority of PNES studies have been conducted within well-resourced settings, and not enough attention has been paid to stigma directed towards these patients. Additionally, very little is known about the PNES population within South Africa. However, what is known, is that multiple barriers exist for healthcare services in South Africa, inclusive of a lack of resources and accessibility of HCPs, which may, in turn, heighten stigma.

This study thus aimed to explore HCPs' stigma towards people with PNES. Particular focus was given to understanding HCPs' experience and knowledge of PNES, discovering the attitudes held by HCPs towards working with PNES as a mental health condition, and exploring HCPs' views of how their stigma manifests towards people with PNES.

Thirteen HCPs, who are specialised in the diagnosis and/or treatment and management of PNES, were recruited through purposive and snowball sampling, and formed the final participant group. Semi-structured individual interviews with broad open-ended questions were utilised to obtain in-depth information from the HCPs. Their responses were analysed through a reflexive thematic process. All themes that were identified during the data analysis stage were conceptualised according to The Health Stigma and Discrimination Framework (Stangl et al., 2019).

Particularly, six main themes were identified, namely: (i) contextual factors (which indirectly influence stigma); (ii) HCPs' frustration with PNES patients; (iii) HCPs' relative level of knowledge; (iv) diagnostic terms; (v) stigma, and (vi) strategies to reduce stigma. The findings suggest that HCPs tended to be overwhelmed with their work schedule owing to limited aid and support, and, in turn, were unable to provide sufficient services to their patients. Subsequently, the HCPs believed that their patients would perceive them as being unfair and stigmatising. Additionally, the HCPs expressed that they experienced great degrees of frustration with their PNES patients, owing to their patients' inability to accept their diagnosis and overall personality. This unfortunately resulted in them developing negative feelings towards their patients. Furthermore, when the HCPs did not have an adequate understanding of PNES, they were less able to shield themselves from non-factual and stigmatising beliefs about the condition. A pertinent problem identified was the use of inappropriate diagnostic terms, as well as the inability to agree on a single diagnostic term for PNES, which consequently led to patients' symptoms being disregarded or misunderstood.

In addition, the HCPs presented with mixed reviews about their own personal stigma, with many of them also viewing their colleagues as the actual stigmatising individuals. Some HCPs reported that a hospital setting contributed towards stigma, whereas others did not hold this belief. The HCPs also disclosed that many HCPs, in general, tend to be dismissive and display negative attitudes towards their PNES patients. It was often noted that HCPs would refer their patients, as they no longer wished to engage with them. Many HCPs also questioned if their patients' symptoms were real. Whilst the HCPs were able to share their perspectives on stigma towards people with PNES, they also provided valuable insights in relation to strategies to reduce stigma, thus demonstrating their genuine interest in wanting the best outcomes for their patients.

This current study is the first to explore stigma towards people with PNES within South Africa. Further research is needed in relation to this topic in order to raise more awareness about PNES and stigma.

Keywords: Psychogenic Non-Epileptic Seizures, PNES, stigma, healthcare providers

Opsomming

Psigogeniese Nie-Epileptiese Aanvalle (PNEA) is ʼn geestesgesondheidstoestand waar aanvalle somaties manifesteer as gevolg van sielkundige ongemak. As gevolg van PNEA, word pasiënte wat aanvalle kry wat van 'n sielkundige, eerder as 'n fisiologiese oorsprong is, dikwels beskou as onvoorspelbaar en minder verdienstelik vir sorg deur gesondheidsorgverskaffers (GSV). Dit hou hoofsaaklik verband met die algemene houding wat in die breër gesondheidsorgstelsel gehuldig word dat PNEA nie as 'n kliniese entiteit beskou moet word nie, asook GSV wat 'n relatiewe beperkte kennis oor die toestand het. Gevolglik staar PNEA-pasiënte 'n hoë mate van stigma van GSV in die gesig, wat dus 'n negatiewe uitwerking op hul diagnostiese en behandelingsprosedures het.

Boonop is daar beperkte bewustheid oor stigma teenoor mense met PNEA. Die meerderheid PNEA-studies is uitgevoer binne omgewings met goeie hulpbronne, en nie genoeg aandag is geskenk aan stigma wat op hierdie pasiënte gerig is nie. Boonop is baie min bekend oor die PNEA-bevolking binne Suid-Afrika. Wat egter bekend is, is dat daar verskeie hindernisse vir gesondheidsorgdienste in Suid-Afrika bestaan, insluitend 'n gebrek aan hulpbronne en toeganklikheid van GSV, wat weer stigma kan verhoog.

Hierdie studie het dus ten doel gehad om GSV se stigma teenoor mense met PNEA te ondersoek. Spesifieke fokus is gegee aan die verstaan van GSV se ervaring en kennis van PNEA, die ontdekking van die houdings wat deur GSV gehuldig word teenoor die werk met PNEA as 'n geestesgesondheidstoestand, en die ondersoek van GSV se sienings van hoe hul stigma teenoor mense met PNEA manifesteer.

Dertien GSV, wat in die diagnose en/of behandeling en bestuur van PNEA gespesialiseerd is, is deur doelgerigte en sneeubalsteekproefneming gewerf, en het die finale deelnemergroep gevorm. Semi-gestruktureerde onderhoude met breë oop vrae is gebruik om in-diepte inligting van die HCP's te verkry. Hulle antwoorde is deur 'n refleksiewe tematiese proses ontleed. Alle temas wat tydens die data-analise-stadium geïdentifiseer is, is gekonseptualiseer volgens die *Health Stigma and Discrimination Framework* (Stangl et al., 2019).

Spesifiek, ses hooftemas is geïdentifiseer, naamlik: (i) kontekstuele faktore (wat stigma indirek beïnvloed); (ii) GSV se frustrasie met PNEA-pasiënte; (iii) GSV se relatiewe vlak van kennis; (iv) diagnostiese terme; (v) stigma, en (vi) strategieë om stigma te verminder. Die bevindinge dui daarop dat GSV geneig was om oorweldig te word met hul werkskedule as gevolg van beperkte hulp en ondersteuning, en op hul beurt nie in staat was om voldoende dienste aan hul pasiënte te verskaf nie. Daarna het die GSV geglo dat hul pasiënte hulle as onregverdig en stigmatiserend sou beskou. Daarbenewens het die GSV uitgespreek dat hulle groot mate van frustrasie met hul PNEA-pasiënte ervaar het, as gevolg van hul pasiënte se onvermoë om hul diagnose en algehele persoonlikheid te aanvaar. Dit het ongelukkig daartoe gelei dat hulle negatiewe gevoelens teenoor hul pasiënte ontwikkel het. Verder, wanneer die GSV nie 'n voldoende begrip van PNEA gehad het nie, was hulle minder in staat om hulself te beskerm teen nie-feitelike en stigmatiserende oortuigings oor die toestand. 'n Pertinente probleem wat geïdentifiseer is, was die gebruik van onvanpaste diagnostiese terme, sowel as die onvermoë om oor 'n enkele diagnostiese term vir PNEA saam te stem, wat gevolglik daartoe gelei het dat pasiënte se simptome verontagsaam of misverstaan is.

Daarbenewens het die GSV gemengde resensies oor hul eie persoonlike stigma aangebied, met baie van hulle wat ook hul kollegas as die werklike stigmatiserende individue beskou het. Sommige GSV het gerapporteer dat 'n hospitaalomgewing bygedra het tot stigma, terwyl ander nie hierdie oortuiging gehuldig het nie. Die GSV het ook onthul dat baie GSV in die algemeen geneig is om minagtend te wees en negatiewe houdings teenoor hul PNEA-pasiënte te toon. Daar is dikwels opgemerk dat GSV hul pasiënte sou verwys, aangesien hulle nie meer by hulle betrokke wou wees nie. Baie GSV het ook bevraagteken of hul pasiënte se simptome werklik was. Alhoewel die GSV in staat was om hul perspektiewe oor stigma teenoor mense met PNEA te deel, het hulle ook waardevolle insigte verskaf met betrekking tot strategieë om stigma te verminder, en sodoende hul opregte belangstelling getoon om die beste uitkomste vir hul pasiënte te wil hê.

Hierdie huidige studie is die eerste wat stigma teenoor mense met PNEA binne Suid-Afrika ondersoek. Verdere navorsing is nodig met betrekking tot hierdie onderwerp om meer bewustheid oor PNEA en stigma te kweek.

Kernwoorde: Psigogeniese Nie-Epileptiese Aanvalle, PNEA, stigma, gesondheidsorgverskaffers

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Dedication

In loving memory of my maternal grandmother, Krishnavanie Moodley.

There are no words to express how grateful I am to you. Since I came into this world, you have loved me unconditionally, unlike anyone else. Your kind words and care will be treasured forever in my heart. Thank you for believing in me and always wanting the best for me. You are a light that continues to shine in my life, irrespective of you no longer being here in the present. This one is for you Ma!

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List of Abbreviations

APA	American Psychiatric Association
BAI-PC	Beck Anxiety Inventory- Primary Care
BPD	Borderline personality disorder
CASE-epilepsy	Communication and Attitudinal Self-Efficacy – Epilepsy measure
CBT	Cognitive-behavioural therapy
CT	Computed tomography
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EEG	Electroencephalogram/Electroencephalography
GP	General Practitioner
GPs	General Practitioners
HCP	Healthcare provider
HCPs	Healthcare providers
HREC	Health Research Ethics Committee
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
MEG	Magnetoencephalography
MMPI	Minnesota Multiphasic Personality Inventory
MRI	Magnetic resonance imaging
NHRD	National Health Research Database
PNES	Psychogenic Non-Epileptic Seizures
PTSD	Post-traumatic stress disorder
USA	United States of America
VEEG	Video-electroencephalogram
WHO	World Health Organization

Chapter 1: Introduction

1.1. Introduction, Research Problem, and Rationale

Psychogenic Non-Epileptic Seizures (PNES) is a condition characterised by seizures which are not due to ictal epileptiform discharges in the brain that result in epilepsy, but which rather, are the result of psychological trauma. These seizures involve a paroxysmal disturbance in behaviour and cognitive functioning in relation to memory and consciousness (Brown et al., 2011). It typically develops during adolescence or early adulthood; however, it can occur at any age, and is mostly associated with women (Strutt et al., 2011). Within the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), PNES is categorised as a type of Conversion Disorder (American Psychiatric Association [APA], 2013). Video-electroencephalogram (VEEG) monitoring is regarded as the golden standard for obtaining an accurate diagnosis of PNES. PNES is commonly treated through the use of cognitive-behavioural therapy (CBT) (Carlson & Perry, 2017). Both diagnostic and treatment procedures are often found to be difficult to administer and time-consuming for healthcare providers (HCPs); this is primarily the result of their own lack of experience (du Toit & Pretorius, 2017).

Misunderstandings tend to be common among HCPs owing to PNES being a mental condition that is expressed through bodily symptoms, and marked by psychological distress (du Toit & Pretorius, 2017; Rössler, 2016). This, in turn, results in HCPs developing extreme frustration due to not being able to carry out proper diagnostic and treatment services, owing to their lack of understanding (du Toit & Pretorius, 2017). PNES individuals are also perceived to be different from individuals who have epilepsy, and who experience seizures that are more commonly accepted (Rössler, 2016). Thus, many HCPs tend to develop a form of stigma towards those with PNES.

Stigma is based on being discrediting and discriminatory towards an individual, because they are believed to reflect a characteristic that distinguishes them from the norm (Rössler, 2016). In this instance, due to a patient having seizures that are psychological in nature, rather than physiological, they are seen as being different (Pretorius & Cronje, 2015). Therefore, individuals with PNES do not only have to cope with the devastating effects of their condition, but also the social exclusion and prejudices displayed by society in general, and by HCPs (Pretorius & Cronje, 2015).

Due to the reluctance by many HCPs to become involved in diagnosing and treating PNES, there seems to be a limited amount of research initiatives in this field (Kohrt et al., 2020). Within South Africa especially, there is a lack of resources pertaining to funding and education, which may in turn affect diagnostic and treatment outcomes (Mhlanga & Garidzirai, 2020), and influence the awareness of PNES. Stigmatising attitudes may develop due to PNES not being properly understood in South Africa, resulting in individuals with PNES being perceived as different from others (Pretorius & Cronje, 2015; Mhlanga & Garidzirai, 2020). Owing to the limited awareness and understanding of PNES, this may in specific cases provide the justification for PNES individuals to be treated immorally. International studies have provided limited attention towards exploring PNES and stigma, with most studies only taking into the account the patients' perspective rather than the HCPs' perspective (Annandale et al., 2022). Furthermore, there have been no studies in South Africa that have primarily explored stigma in relation to PNES. It is thus important to conduct research in South Africa within this field. My study specifically aims to explore HCPs' stigma towards people with PNES.

1.2. Research Question

In this proposed study the following research question will be addressed:

- What are HCPs' stigma towards people with PNES?

1.3. Research Aims

This proposed study aims to explore HCPs' stigma towards people with PNES with the primary focus on:

- Understanding HCPs' experience and knowledge of PNES;
- Discovering the attitudes held by HCPs towards working with PNES as a mental health condition, and
- Exploring HCPs' views of how their stigma manifests towards people with PNES.

1.4. Definition of Key Terms

1.4.1. Definition and Diagnosis of Psychogenic Non-Epileptic Seizures (PNES)

PNES is characterised by episodes which are paroxysmal and altered, and involve sensation, movement, and experiences which are seen to mimic epileptic seizures (Brown et al., 2011). However, these types of seizures are not caused by ictal epileptiform discharges in the brain, but rather, are the result of psychological distress. The symptoms of PNES involve a sudden disturbance in behaviour, affect, memory, or consciousness (Brown et al., 2011).

Research studies have indicated that it takes a prolonged period of time with an average delay of seven years and the use of VEEG monitoring equipment, to obtain a confirmed diagnosis of PNES (Brown et al., 2011; Kerr et al., 2016). According to the DSM-5, PNES is recognised as a form of dissociative disorder (abnormal nervous system functioning), or somatic symptom (in relation to the body) and related disorders (APA, 2013). This entails that they are viewed as involuntary responses to physical, emotional, and social distress (APA, 2013; Brown et al., 2011).

In the DSM-5, PNES falls under the main branch referred to as Conversion Disorders. In order to receive a diagnosis (APA, 2013), (i) an individual must display one or more symptoms of altered voluntary motor or sensory functioning, (ii) there needs to be an incompatibility between the symptom(s) and neurological condition, (iii) it should not be able to be better explained by any other medical or mental disorder, and (iv) the symptom(s) should result in severe impairment of functioning in relevant areas of one's life, and thereby warrant the need for evaluation.

1.4.2. Definition of Stigma

Stigma refers to the belittling or discrediting of an individual due to having displayed or represented a certain trait that differentiates them from others (Rawlings et al., 2017). Such an individual is violating a norm of a social unit, where it is believed that individuals have to behave in specific ways according to the context. The individual is likely to experience a form of labelling, stereotyping, intolerance, isolation, and social status loss (Link & Phelan, 2001). There is an increased tendency for individuals with mental illnesses to be the victims of stigmatisation. An individual tends to be defined according to their illness, as opposed to who they fully are as a human being (Rawlings et al., 2017).

Mental health stigma itself is differentiated into social stigma and perceived stigma (Latalova et al., 2014). Social stigma refers to actions that are discriminatory and targeted towards individuals because of their diagnosis (Latalova et al., 2014). An example of social stigma provided by Dworetzky (2015), is where HCPs state that patients with PNES are different to themselves, are less useful to society, and do not take responsibility for their symptoms. Thus, the patients are discriminated against by HCPs (Dworetzky, 2015). Perceived stigma is where the patient internalises perceived discriminatory thoughts (Latalova et al., 2014). A possible example of this can be seen in how patients with PNES continue to be treated negatively, and are exposed to comments such as that they are "useless" or "faking symptoms" (Rawlings et al., 2017; Sahaya et al., 2012). Eventually these patients start to believe that these comments are true, and no longer have the motivation to seek further treatment (Rawlings et al., 2017; Rivera-Segarra et al., 2019; Sahaya et al., 2012). Individuals with PNES are also stigmatised as they are believed to be contagious, possessed by spirits, and serve as a sign of evilness in some cultures (Rawlings et al., 2017).

1.4.3. Definition of Healthcare Providers (HCPs)

According to the World Health Organization [WHO] (2013), HCPs are individuals who pursue specific actions with the main objective to improve the health of individuals. Their occupation entails protecting the lives of community members (WHO, 2013). HCPs ensure that the health of individuals remains adequate by applying principles and following procedures obtained from evidence-based care and medicine (WHO, 2013). They address the needs of the population by studying, diagnosing, treating, and preventing human sicknesses, injuries, and other physical or mental conditions (WHO, 2013). They also offer advice and engage in curative and preventative measures in order to meet health needs. Some HCPs also conduct research, and increase or contribute to the development of theories, concepts, and operational methods (WHO, 2013). They may also serve as a means of supervision to other health workers (WHO, 2013). The healthcare team that tends to work with patients with PNES include neurologists, psychiatrists, psychologists, and nurses (Sahaya et al., 2012).

1.5. Chapter Overview

Chapter 1 served as an introduction for means of introducing readers to the overall study topic on PNES and stigma. The current research problem and rationale for this study, research question and aims, as well as key concepts were described.

Chapter 2 includes the provision of pertinent literature regarding PNES nosology, historical overview, signs and symptoms, epidemiology, aetiology and risk factors, diagnosis, treatment, level of burden, and prognosis. The PNES patients’ experiences of stigma from HCPs, as well as the HCPs’ perspectives on stigma towards people with PNES, are addressed.

Chapter 3 presents the elaboration, application, and critique of The Health Stigma and Discrimination Framework, formulated by Stangl et al. (2019), in relation to PNES.

Chapter 4 outlines the research methodological approach for this study. The research design, participants and sampling strategies, data collection and analysis procedures are explained further. The chapter finishes with a discussion on the trustworthiness processes required to ensure the rigour of the study, and ethical considerations.

Chapter 5 includes an overview of the main findings of this study as obtained from the semi-structured interview process, and is presented through the lens of the theoretical framework. Reflexive thematic principles proposed by Braun and Clarke (2019) are utilised in order to provide a qualitative description of the findings.

Chapter 6 discusses the main findings of this study through further exploration of the theoretical framework, and in correspondence to the relevant literature identified. There will also be a discussion of the limitations of this study, and recommendations for future research purposes. The chapter closes with concluding remarks regarding this current study.

Chapter 2: Literature Review

2.1. Introduction

In this chapter, I provide an overview of the current literature in relation to PNES, stigma, and HCPs. Owing to the complicated nature of PNES as a mental condition, a detailed discussion about the clinical elements of the disorder, is also provided.

My discussion begins with the nosology and historical background of PNES. Following this, the PNES signs and symptoms, epidemiology, and aetiology and risk factors, are provided. An outline of factors related to the diagnosis, and treatment of PNES, is then presented within this chapter. Thereafter, the level of burden, as well as the prognosis/outcomes for patients, are discussed. PNES patients' experience of stigma displayed by HCPs, is identified and explained further. I then conclude this chapter with a discussion of HCPs' perspectives of their stigma towards people with mental illnesses and PNES.

2.2. PNES Nosology

PNES is viewed as a neuropsychiatric condition that results in loss of self-control and causes transient alterations of consciousness (Yeom et al., 2021). It mainly occurs in vulnerable individuals who have experienced a form of psychological trauma, whereby their seizures serve as a bodily expression of a distressed mind (Yeom et al., 2021). It is regarded as a heterogenous condition that has notable comorbid psychiatric, neurologic, and personality pathologies, which often in turn leads to HCPs misunderstanding, misdiagnosing, mistreating, and not providing adequate recognition for the condition (Rady et al., 2021; Yeom et al., 2021).

Currently, PNES is typically categorised as a manifestation of a conversion or somatoform disorder (APA, 2013). Within the DSM-5, PNES is specifically classified as the subtype, "with attacks or seizures" under the diagnostic criteria for conversion disorders (functional neurological symptom disorder) (APA, 2013). In the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), PNES is categorised as a conversion disorder with seizures or convulsions, which is inclusive of dissociative convulsions (WHO, 1990). Both the DSM-5 and the diagnostic code, ICD-10, provide relevant insights into the neurobiological underpinnings of PNES (Vasta et al., 2018). As previously stated in Chapter 1, VEEG equipment is required to provide an accurate diagnosis of PNES; however, many HCPs view this form of assessment as expensive, non-compulsory, and involving unnecessary hospitalisation for patients (Vasta et al., 2018). Furthermore, PNES, rather than epileptic seizures, occur in more than 20% of patients referred to epilepsy units for epileptic refractory seizures (seizures that are not able to be controlled by medication), rather than psychiatric care. Therefore, this demonstrates that there is confusion among HCPs in understanding the psychological components of the condition, owing to it not being initially taken into consideration (Vasta et al., 2018).

PNES is often not regarded as a unitary disorder, but rather as one with multiple aetiologies and manifestations (Griffith & Szaflarski, 2010; Reuber et al., 2005). Owing to PNES not falling under a single distinct psychopathological category (as seen in the differential classifications of the DSM-5 and ICD-10), confusion and categorisation difficulties are likely to arise (Griffith & Szaflarski, 2010; Reuber et al., 2005). Such frustration could in turn increase HCPs' stigmatising attitudes, and thus it is suggested that more attention should be paid to formulating and recognising PNES as a clinical entity (Jafari et al., 2020).

2.3. Historical Overview

The origins of PNES can be traced back to the Middle Ages where the condition was viewed as a form of witchcraft, and deemed a punishable crime at the time (Institoris et al., 1948). The social stigma displayed during this period resulted in individuals with seizures experiencing isolation, rejection, and exclusion from educational services (Ba-Diop et al., 2014; Institoris et al., 1948). The physician, Edward Jorden, was the first to recognise symptoms such as paralyses and convulsions related to seizures, as a form of anxiety and uneasiness manifested by the mind, and commonly occurring in the female sex (Jorden, 1603). This led to a more centred focus on the mind and interest in the notion of hysteria.

In the 1960s and 1970s, PNES was viewed as a form of hysteria (Breuer & Freud, 1955; Kurcgant et al., 2011). The rise of psychoanalysis in the 19th century aided in the understanding of PNES (Breuer & Freud, 1955). Hysterical symptoms of PNES were related to the unconscious. In order to deal with inner psychological conflicts and trauma, the unconscious mind served as a mechanism to convert inner conflicts into physical symptoms (Breuer & Freud, 1955).

In 1962, within the second edition of the DSM, hysteria was classified into two categories, namely conversion-type historical neurosis and dissociative-type hysterical neurosis, with PNES being more so associated with the conversion type (APA, 1968; Kurcgant et al., 2011). Patients with this type of disorder were viewed as dramatising their life experiences and having a hysterical personality; this in itself was a stigmatising viewpoint, which was held by many HCPs (Kurcgant et al., 2011). After more research was conducted, it was identified that those who presented with a form of hystereo-epilepsy, in fact, did not have a hysterical personality (Kurcgant et al., 2011; Stefanis et al., 1976; Trimble, 2010).

Whilst some professionals viewed the diagnosis of hysteria to be positive, in that it directed HCPs towards a psychopathological underpinning, some worried that it would result in the pejorative use of the term hysteria and lead to inadequate clinical utility (Alam & Merskey, 1992; Kurcgant et al., 2011; Stefanis et al., 1976; Trimble, 2010). Researchers also argued that there should be a separation between hysteria and hysterical personality disorder, in order to eliminate prejudiced views. Such a separation remained blurred over the decades, with only subtle changes made to the DSM (Alam & Merskey, 1992; Kurcgant et al., 2011; Stefanis et al., 1976; Trimble, 2010).

From the 1980s onwards, a limited amount of literature was published about PNES. However, during this period, VEEG equipment came to the rise and influenced the nosological classification of PNES (Kurcgant et al., 2011). More attention was paid to the idea of a neurological basis for the condition. This led to discussions among psychiatrists about the issues surrounding hysteria and the realisation that patients were being misdiagnosed with epilepsy (Kurcgant et al., 2011). The terms hysteria and neurosis were removed from the third edition of the DSM (APA, 1980). Large scale psychological testing and standardised interviews were conducted during this period of time, to identify cognitive, personality, and other psychiatric factors related to PNES (Henrichs et al., 1988; Kurcgant et al., 2011; Vanderzant et al., 1986; Wilkus et al., 1984). Owing to such assessment, the 1990s were marked with a focus on post-traumatic stress disorder (PTSD) and dissociative disorders (Betts & Boden, 1992; Kurcgant et al., 2011). Particularly, the relationship between abuse and PNES patients' biographies became apparent, thus, leading to the idea that patients' symptoms were the result of a psychological trauma (Betts & Boden, 1992; Kurcgant et al., 2011; Trimble, 2010).

It can be seen that PNES is marked by a range of name iterations including hysteria, and hystereo-epilepsy (Kurcgant et al., 2011; Trimble, 2010); more recent terms include pseudoseizures, psychogenic non-epileptic spells, and psychogenic non-epileptic attacks, along with PNES being commonly used (Ekanayake et al., 2017; Smith, 2014). The use of accurate terminology is not only useful to patients who have to form an understanding of their specific diagnosis, but it in turn can also result in better care outcomes and procedures, and shape the attitudes of HCPs (Brigo et al., 2015). For example, by using the term PNES, one is able to reduce stigmatising ideas such as patients being “crazy” or “possessed”, as these ideas are typically associated with the diagnostic term, hysteria (Kurcgant et al., 2011). However, it is also noted that the recent terms used today, such as PNES, are problematic (Huff & Murr, 2021). It reinforces the idea that events are of a psychiatric origin and are not related to epileptic seizures. Patients are thus defined according to the characteristics that they lack, instead of those that they have (Huff & Murr, 2021). Many patients prefer the terms “functional seizure” or “dissociative seizure” over PNES, as it lessens the link to having a psychological condition, and subsequently reduces their levels of experienced stigma and seizure burden (Loewenberger et al., 2021).

Moreover, the use of just “psychogenic”, “dissociative” or “conversion”, does not allow for the recognition of the complex aetiology of the condition, and leads to confusion among HCPs (Asadi-Pooya et al., 2020). By focusing only on “psychogenic”, HCPs take into consideration the psychological aspects of the condition, while neglecting the dysfunction that occurs in executive control, and regions of the brain involved in cognitive processing, and somatic functioning (Asadi-Pooya et al., 2020). Using a term that does not have a negative connotation, and one that offers a detailed description of the pathophysiology of the condition, in turn, has a positive effect on how HCPs view the patient community, and can also lead to the acceptance of the diagnosis as a clinical entity (Asadi-Pooya et al., 2020). The lack of universally accepted terminology among HCPs remains a controversial area, and more efforts are required to form a term that will reduce the stigma associated with this condition (Asadi-Pooya et al., 2020). This specific study will use the term PNES to refer to the mental health condition, as current literature, both internationally and nationally, commonly refers to the term PNES to describe seizures which are caused psychologically (Asadi-Pooya et al., 2020; Hartwig & Pretorius, 2019).

Many advances have been made in diagnostic and treatment procedures for PNES; however, the classification of PNES in the fields of neurology, psychiatry, and psychology, remains complicated. This is owing to PNES being referred to as a disorder that rests on the border between neurology and psychiatry (Baslet et al., 2015; Kanner, 2010; Kurcgant et al., 2011). It is also often the result of a lack of communication between these disciplines and the understanding of each other’s procedures. Thus, more collaboration is needed among these disciplines in order to heighten the understanding of PNES and eliminate stigmatising experiences associated with the condition (Baslet et al., 2015; Kanner, 2010; Kurcgant et al., 2011).

2.4. Signs and Symptoms

Objective evidence of a disease that can be identified by a HCP is referred to as a sign (Knapp, 2018). In contrast, a symptom is any subjective evidence of the disease that is identified by the patient (Knapp, 2018). The PNES signs that are reliably distinguished from epilepsy include patients presenting with a fluctuating course and seizures that last for a long duration, asynchronous or side-to-side head and body movements, eye closure and crying at the ictal (during seizure) onset, pelvic thrusting, and the ability to recall information after seizure episodes (Perez & LaFrance Jr, 2016). Urinary incontinence, tongue biting and opisthotonos (muscle spasms resulting in the head, neck, and spine arching backwards) are also viewed as signs of PNES, but do not always serve as a significant factor to differentiate PNES patients from those with epilepsy (Perez & LaFrance Jr, 2016).

There are a limited number of studies that have investigated PNES patients' subjective experience of their condition. A specialist in neurology and neurosurgery at Tampa General Hospital, Benbadis (2018), states that the most common symptoms provided by PNES patients include back arching, side-to-side head shaking, stuttering, weeping, and asynchronous movements that occur bilaterally such as appearing to ride a bicycle. Such signs and symptoms are especially important when it comes to obtaining a correct diagnosis of PNES (Benbadis, 2018).

2.5. Epidemiology

2.5.1. International and National Incidence and Prevalence Rates of PNES

Bompaire et al. (2021) have reported the estimated PNES incidence to be 1.4-4.9/100,000 individuals per year. In addition, according to epileptic clinic reports from population-based studies conducted in developed countries, 5-10% of outpatients and 20-40% of inpatients have been reported to have PNES (Alsaadi & Marquez, 2005; Asadi-Pooya & Sperling, 2015; Martin et al., 2003). A cross-sectional study done in a hospital in Tanzania, in sub-Saharan Africa, identified that only 22 out of 2,040 patients displayed PNES, meaning that PNES is a rare condition (Dekker et al., 2018). However, it is also noted that due to the lack of resources and understanding of PNES in developing countries, it is hardly diagnosed (Dekker et al., 2018). In South Africa, a study based on incidence was conducted in a private clinic in Johannesburg. The results showed that 50% of patients had epilepsy, and 50% of patients had PNES (Anderson et al., 2017); thus, demonstrating a 10-30% higher average of PNES than in developed countries.

According to Benbadis and Hauser (2000), the global prevalence rate of PNES is estimated to be two to 33 per 100 000 individuals. In general, there is a limited amount of literature based on PNES prevalence rates, and within South Africa, the prevalence rate of PNES is unknown. Epidemiological studies are often difficult as it requires a large representative sample, and is overall too expensive to conduct. However, Pretorius and Cronje (2015) conducted a study about the demographic variables of PNES patients in South Africa, and were informed by a neurologist at the Unit for Epilepsy at Mediclinic Constantiaberg, that a large number of individuals are diagnosed per month with the condition. It must be noted that the clinic has patients from across the country, owing to its recognition for being the most equipped to diagnose PNES. This suggests that PNES is a potentially common disorder in South Africa.

2.5.2. Age

There is no discrimination amongst age for affected populations, with PNES being diagnosed across the life-span. However, it is noted to occur more frequently in adolescence and/or young adulthood (Asadi-Poya & Sperling, 2015). When taking into consideration the approximate incidence or prevalence in relation to age, one must note that PNES is largely undiagnosed and there is a 7–10-year delay of achieving an accurate diagnosis (Brown et al., 2011). A study in Brazil showed that 53 children aged between 7-17, with documented PNES experienced an average delay of 17.6 months prior to proper PNES referral, leading to the age of onset being elongated (Valente et al., 2017). In the South African study conducted by Anderson et al. (2017), in their sample of 123 participants, the age of PNES patients was reported to range from 12-69 years of age, thus, showing the age variability of PNES.

2.5.3. Gender

PNES is noted to occur more frequently in the female sex (Benbadis & Hauser, 2000). A vast number of studies has found the ratio between females and males to be 3:1, showing that the condition is predominant amongst women (Lesser, 1996; Noe et al., 2012; Sigurdardottir & Olafsson, 1998; Szaflarski et al., 2000). A study by Bahrami et al. (2019), in a sample of 330 patients, only showed a slight difference, with the sex ratio of 216:114 in favour of females. An exception to these findings was those that were obtained from China, where the ratio of females to males was found to be 1:1 (An et al., 2010). The South African study by Anderson et al. (2017) had a sample consisting of 73% of females; thus, again demonstrating that PNES is more common among females. It is also noted that the clinical course for PNES may differ among men and women. A study done by Korucuk et al. (2018), with a sample of 41 patients diagnosed with PNES through the use of VEEG, identified that

PNES occurred later in women than in men (24.3 years of age versus 17.5 years of age), and that the episode duration of seizures lasted longer in women.

2.6. Aetiology and Risk Factors

2.6.1. Trauma, Abuse, and Stressful Life Events

The association between life adversity and psychological trauma as an aetiological factor for PNES has been recognised since the 19th century, and continues to be an important factor (Popkirov et al., 2019). Childhood maltreatment, including physical and psychological abuse, as well as neglect, are common among PNES patients (Popkirov et al., 2019). Studies have found structural and functional changes in the adult brain, and reduced grey matter in limbic areas, as a result of childhood maltreatment, and abnormal stress and emotional regulation (Herringa, 2017; Paquola et al., 2016). PNES patients who display severe and convulsive seizures, and who have high emotional triggers, tend to have a history of sexual trauma (Selkirk et al., 2008). PNES can be manifested through trauma by recalling memories, resulting in an ictal experience involving traumatic flashbacks (Betts & Boden, 1992; Popkirov et al., 2019). As a result, it has been theorised that PNES is actually a form of PTSD, where non-epileptic seizures serve as a reaction towards experiencing flashbacks or preventing intrusive painful memories from arising, thus, being viewed as a defence mechanism (Betts & Boden, 1992, Zeng et al., 2018).

2.6.2. Gender and Sex

As stated, in section 2.5.3., females are more frequently diagnosed with PNES than males, with the ratio being 3:1 (Noe et al., 2012). This type of occurrence tends to be explained from a social or neurobiological viewpoint (Asadi-Poya, 2016; Reuber et al., 2007). From a social perspective, researchers believe that the higher prevalence rate linked to females is because they are more likely to experience sexual, physical, and emotional trauma (Reuber et al., 2007). From a neurobiological perspective, PNES is manifested as a result of inherent functional connectivity differences in the brain regions of males and females (Asadi-Pooya, 2016). Such brain regions are involved in emotional and cognitive processing, which affect how the sexes respond to psychological or physical trauma, thus resulting in women being more prone to psychopathology, including PNES (Asadi-Pooya, 2016).

2.6.3. Dysfunctional Relationships and Attachment

Childhood trauma associated with PNES is often linked to the development of dysfunctional attachment styles in adulthood, with a majority of PNES patients having difficulties in forming and maintaining interpersonal relationships (Brown & Reuber, 2016a).

Typical relationships that PNES patients have with their family, therapist, and larger social environment, are characterised by avoidance, insecurity, and anxiety (Green et al., 2017; Wardrope et al., 2019). When interpersonal challenges arise, PNES can serve as an unintentional escape mechanism where individuals enter into a seizure state to avoid interpersonal distress (Brown & Reuber, 2016b).

2.6.4. Personality

2.6.4.1. Personality Disorders. The prevalence of personality disorders is high among PNES patients. Borderline personality disorder (BPD) appears to be the most noted phenotype, with obsessive-compulsive personality disorder also present in some cases (Popkirov et al., 2018). BPD is associated with childhood trauma, which often serves a trigger for dissociative symptoms (Popkirov et al., 2018). Emotional dysregulation, which is noted among many patients with PNES, is also witnessed in patients with BPD. Such dysregulation is viewed as an important factor in the pathophysiology of seizures (Jungilligens et al., 2019). As stated in the previous section, PNES patients tend to have difficulties with interpersonal relationships, and the same is true for those with BPD (Green et al., 2017; Wardrope et al., 2019). It is thus important to identify underlying comorbid personality disorders with PNES, in order to achieve a better prognosis for PNES patients.

2.6.4.2. Personality Traits and Factors. Currently, there is no distinct personality profile that has been identified for PNES. However, it is noted that PNES patients have certain personality traits that distinguish them from patients with epilepsy. The most recognised personality measures used in PNES studies so far are the Minnesota Multiphasic Personality Inventory (MMPI) and the MMPI-2 (Dodrill, 2010). In comparison to epilepsy patients, patients with PNES have displayed higher scores on various personality subscales of anxiety (Cragar et al., 2005; Hill & Gale, 2011; Owczarek, 2003; Thompson et al., 2010), modesty (Cragar et al., 2005), and anger hostility (Cragar et al., 2005). They have also scored low on measures of gregariousness and trusting others (Cragar et al., 2005; Kranick et al., 2011).

2.6.5. Coping Mechanisms

PNES patients are suggested to have a particular set of coping strategies, mainly being recognised as avoidance (Goldstein et al., 2000) and distancing (Cronje & Pretorius, 2013). It is noted that patients with PNES may have a lack of emotional awareness and expression, and thus express their psychological states through dissociation (Goldstein et al., 2000; Urbanek et al., 2014).

2.6.6. Other Psychiatric Comorbidities

Patients with PNES have a high prevalence of comorbid conditions in comparison to patients with epilepsy (Hovorka et al., 2007; Mökleby et al., 2002). The most common comorbid disorders associated with PNES include depression, as well as anxiety disorders, specifically PTSD (Abubakr et al., 2003; Alsaadi & Shahrour, 2014; Diprose et al., 2016; Griffith & Szaflarski, 2010; LaFrance Jr & Devinsky, 2002; Reuber, 2008). It is still unclear how these comorbid conditions interact or influence PNES, but it is suggested that comorbidity may arise due to having PNES for a prolonged period of time (Bodde et al., 2009a).

2.6.7. Integrative Theory of PNES

There tends to be a lack of focus given to the mechanisms that play a role in the development and maintenance of PNES, with many studies only taking into consideration the predisposing, precipitating, and perpetuating factors (Brown & Reuber, 2016b). In order to fill the necessary gaps of previous models, Brown and Reuber (2016b) have formulated the Integrative Theory of PNES (depicted in Figure 1), through which they integrate theories that already exist, as well as findings based on PNES' aetiological factors. The researchers use the Integrative Cognitive Model of medically unexplained symptoms as their foundation, and hold the perspective that PNES occur due to seizure scaffold. Seizure scaffold refers to internal and external triggers which tend to be traumatic, and which automatically activate rogue mental representation (Brown & Reuber, 2016b). Mental representations are the result of experience and learning, and are made up of cognitive-emotional-behavioural action programmes that are formulated through a combination of inherent schema (for example, how one responds to fear) (Brown & Reuber, 2016b). The different manifestations recognised among the PNES population are often associated with the activation of seizure scaffold, which may be the outcome of abnormal arousal, or emotional and cognitive processing (Brown & Reuber, 2016b).

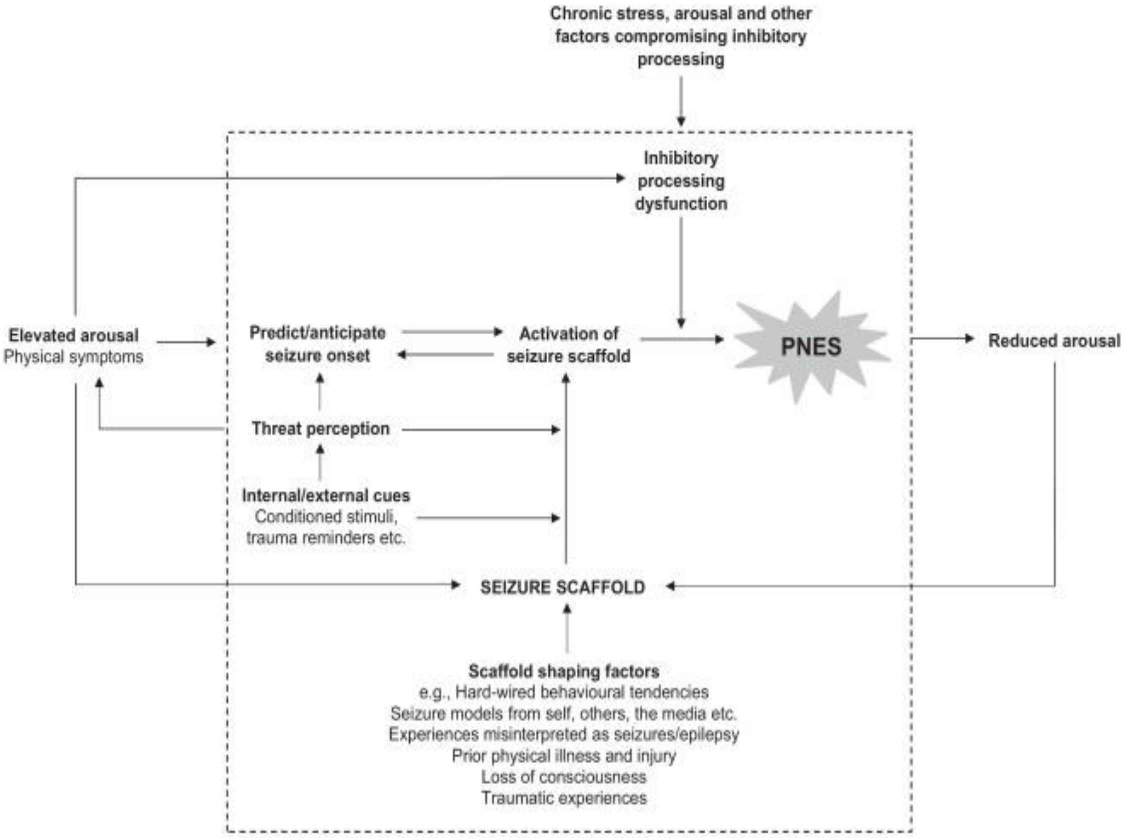

Figure 1: *Hypothesized sequence of events in PNES* (reproduced with permission [Appendix A] from Brown & Reuber, 2016b).

2.7. Diagnosis

Achieving an accurate diagnosis of PNES is time-consuming and often patients wait on average for seven-years, to obtain a confirmed diagnosis (Brown et al., 2011). As mentioned, PNES tend to be commonly misdiagnosed with epilepsy, with further complications existing due to 5-20% of patients presenting with both conditions concurrently (Alsaadi & Marquez, 2005; Benbadis et al., 2001; Griffith & Szaflarski, 2010; LaFrance Jr & Benbadis, 2011; LaFrance Jr & Devinsky, 2002). However, various other conditions such as sleep disorders, paroxysmal dyskinesia, transient ischemic attacks, and movement disorders, also need to be differentiated from PNES, which may result in further challenges for HCPs (Jafari et al., 2020). Thus, it is substantial that a patient’s clinical history should be noted, and seizure episodes should be directly observed by a specialist (Jafari et al., 2020).

The ability to obtain an informed correct diagnosis helps in many ways. Firstly, it eliminates the possibility of using harmful antiepileptic medication for PNES patients (Bodde et al., 2009a; Brown et al., 2011; Lee, 2010). Secondly, the financial burden for both patients and hospitals is lessened due to not needing to attend various healthcare assessments other than those required (Gene-Cos & Ring, 2005). Thirdly, it allows HCPs to provide a treatment plan that is catered to the patient’s specific needs (Alsaadi & Shahrour, 2014; Reuber et al., 2003). Fourthly, a diagnosis can be therapeutic in that it provides patients with a sense of relief and validation for their symptoms (Iriarte et al., 2003). Finally, when HCPs are able to provide an accurate diagnosis, this, can, in turn, reduce the effects of stigma by demonstrating their knowledge of the condition, showing empathic communication of the diagnosis, and genuine care for their patients’ outcome after the diagnosis is provided (Nyblade et al., 2019).

2.7.1. Diagnostic Methods

The diagnosis of PNES typically occurs through stages; namely: 1. Suspicion, 2. Diagnosis, and 3. Confirmation (Brown et al., 2011). These are further explained below.

2.7.1.1. Stage One: Suspicion. HCPs have the tendency to rely on signs and symptoms displayed by seizure patients in order to obtain a diagnosis; this was particularly true for time periods before any advancements in technology were noted and discovered (Jordan, 2007). However, even when relevant technological equipment was available, such as that used to preform EEGs, HCPs still paid particular attention to the semiology within the initial phases of clinical evaluation (Iriarte et al., 2003; Syed et al., 2011).

As previously stated in section 2.6., there are multiple aetiological factors that are related to PNES. There have also been significant attempts in determining which clinical features would be useful in obtaining a differential diagnosis between epilepsy and PNES (Hocaoglu, 2017). The signs and behaviours that are deemed the most useful in obtaining this differential diagnosis is noting the duration of the seizure; seizures that happen frequently, occurring more than once a day, tend to be associated with PNES, whilst epileptic seizures generally last only a few minutes (Hocaoglu, 2017). PNES patients also show a pattern of having seizures in a specific environment or time, whereas epilepsy patients do not show this pattern (Hocaoglu, 2017). Individuals with epileptic seizures also experience a complete loss of consciousness during their episodes, whilst PNES patients do sustain consciousness, and can hear, but are not able to respond (Hocaoglu, 2017). Other important factors include motor movements and reflex changes, and the induction property of seizures (Hocaoglu, 2017). Therefore, it can be seen that the relationship between PNES and semiology is useful in obtaining a diagnosis. It contributes towards raising suspicion as to whether PNES can serve as a differential diagnosis to epilepsy, which is of essence in the prognosis of patients (Brown et al., 2011).

2.7.1.2. Stage Two: Diagnosis. The advent of EEG equipment allowed for the possibility to identify and record electoral brain activity. This includes ictal (during a seizure), interictal (between seizures), and postictal (after seizures) discharges (Fisher et al., 2014). Epileptic seizures are recognised as interictal epileptiform discharges in the brain, and appear in spiked patterns, with unusual brain waves observed during the EEG. Thus, if such a pattern is not identified when a patient presents with seizures, there may be an alternative reason (Ko, 2017).

2.7.1.3. Stage Three: Confirmation. The end of the twentieth century was marked by the contribution of the use of video imaging in combination with EEG equipment. The simultaneous use of video and EEG allows for patients' electoral brain activity, as well as their behaviour, to be tracked over an extended period of time (Benbadis & LaFrance Jr, 2010). A PNES diagnosis can be confirmed if no other aetiological factors similar to epilepsy are seen to have an influence, and if no abnormal results are obtained from the EEG when the patient presents with seizure-like behaviours (Benbadis & LaFrance Jr, 2010). Therefore, VEEG is claimed to be the golden standard for a PNES diagnosis (Benbadis & LaFrance Jr, 2010; Brown et al., 2011).

2.7.2. A Newly Recognised Diagnostic Tool

Magnetoencephalography (MEG) is a newly used neurophysiologic test, which has demonstrated beneficial effects in the diagnosis of both epilepsy and PNES (Boutros et al., 2018; Laohathai et al., 2021). The MEG is a non-invasive method of recording used to measure magnetic fields in the brain's electrical currents. This recording, in turn, helps to identify the exact location of seizures and to map brain functions (Laohathai et al., 2021). The MEG is viewed as offering a higher degree of sensitivity in terms of assessment in comparison to VEEG (Laohathai et al., 2021). The MEG has the ability to pick up on potential fontal-temporal hyperexcitability in the brain, associated with PNES (Boutros et al., 2018). However, more research is required to determine the accuracy of this diagnostic tool for PNES specifically (Boutros et al., 2018). It must be noted that the MEG remains highly inaccessible and scarce. This is often owing to many institutions being unable to afford such equipment, or not having enough aid or priority within the healthcare system to be provided with resources in general (Laohathai et al., 2021).

2.7.3. Diagnostic Alternatives

Due to the heavy reliance on expensive VEEG to rule out epilepsy in order to identify PNES, there have been a range of efforts made with regards to searching for more cost and time effective alternative measures that would assist with differentiating between the two conditions. Particularly, notable research has focused on factors such as (i) locus of control and illness behaviours (Goldstein et al., 2000; Stone et al., 2004), (ii) assessment drawn from neuropsychology and personality (Cragar et al., 2005; Dodrill, 2010), (iii) clinical history in relation to seizure frequency and age of onset (Reuber & Elger, 2003; Syed et al., 2011), (iv) questionnaires based on coping strategies (Goldstein et al., 2000), (v) single photon emission computed tomography (Neiman et al., 2009), (vi) resting state connectivity via functional magnetic resonance imaging (van der Kruijs et al., 2012), (vii) post-ictal prolactin level measurement (Alsaadi & Shahrour, 2014; Cragar et al., 2002), and (viii) variability in heart rate (Ponnusamy et al., 2012). Despite these efforts, VEEG still remains the most effective technique to obtain a valid diagnosis of PNES.

2.7.4. Multifaceted Methods used for Differential Diagnostic Purposes

Possibly, the most significant contribution towards differentiating PNES from epilepsy was made by Syed et al. (2009). These researchers formulated a questionnaire consisting of 53 items based on (i) age of onset, (ii) the occurrence of seizures on a monthly basis, (iii) fibromyalgia, (iv) the Health-Promoting Lifestyle Profile which is a nutritional subscale measure, (v) a subscale based on communication and self-efficacy (CASE-epilepsy), (vi) a measure based on behavioural reaction to illness in terms of limiting behaviour and practical support, (vii) a subscale based on the Multidimensional Locus of Control, and (viii) the Zung Self-Rated Depression Scale (Syed et al., 2009). The use of this questionnaire within epilepsy centres demonstrated the ability to correctly predict PNES with 85% sensitivity, and 85% specificity (Syed et al., 2009). Similar percentages, of 94% sensitivity, and 83% specificity were identified in training centres that utilised the questionnaire (Syed et al., 2009). Whilst the questionnaire is effective, its biggest limitation is the scoring method, which depends on the hybrid neural-Bayesian classifier, resulting in it not being practically useful within healthcare and academic contexts where such expertise tends to be limited (Syed et al., 2009). Irrespective, the study still demonstrates that focus should be given to multifaceted factors when taking into consideration alternative diagnostic methods (Syed et al., 2009).

2.7.5. South African Recognised Diagnostic Problems

Even though VEEG is viewed as the golden standard towards obtaining an accurate diagnosis of PNES, this method appears to be extremely expensive, especially within developing countries (Birbeck, 2010). In South Africa specifically, VEEG monitoring is not accessible by the majority of the population (Pretorius, 2016), with 73% of EEG machines being owned by the private sector (Birbeck, 2010). South African HCPs also do not have an adequate understanding of PNES, which can lead to further complications in diagnostic procedures, such as misdiagnosing patients with epilepsy and holding the stigmatising belief that patients are faking their seizures (Pretorius, 2016).

Cheaper measures identified in international countries tend to use lengthy and complicated scoring algorithm questionnaires, such as the one formulated by Syed et al. (2009) identified in section 2.7.4., or post-ictal prolactin level measurement, which relies on seizure observation (Alsaadi & Shahrour, 2014). Such measures are difficult to utilise in countries such as South Africa where there are limited resources, where medical care is not easily obtainable, and where the ability to provide individual attention to patients for a prolonged period of time is not always possible (Gaede & Versteeg, 2011). More focus needs to be given to raising awareness about PNES in South Africa, and cheaper measures should be deemed valid and reliable for transfer to the South African context, where such measures would most likely need to be translated into South African languages (Gaede & Versteeg, 2011). The most recent study in South Africa, based on differentiating between PNES, epilepsy, and other non-epileptic seizures, was conducted by Vilyte and Pretorius (2019). They looked at various measures of differentiation including the Beck Anxiety Inventory-Primary Care (BAI-PC), based on psychiatric comorbidity within patients; this measure was deemed the most effective. The study suggested that the BAI-PC could be utilised as a means for raising suspicion of PNES as the differential diagnosis to epilepsy and other non-epileptic seizures, owing to it predicting PNES with 80% sensitivity and 89% specificity (Vilyte & Pretorius, 2019). Thus, it is of essence that more research is conducted to implement such diagnostic measures within a South African context.

Other than HCPs and healthcare services being a barrier to diagnostic procedures, patients also have an influence. In South Africa, there tends to be a stigmatising cultural phenomenon where individuals think that their PNES diagnosis is nonsensical and that having an underlying psychological condition cannot be valid (Pretorius & Sparrow, 2015). This often results in complications for further procedures such as treatment plans (Pretorius

& Sparrow, 2015). Stigmatising attitudes in relation to diagnostic and treatment procedures, will be explained in more detail in sections 2.11. and 2.12. of the literature review.

2.8. Treatment

Treatment that is catered towards individuals with PNES involves identifying the underlying psychological problem or psychiatric disorder (Oto & Reuber, 2018). PNES is not treated to the same as for epilepsy, where antiseizure medication is used. Such medication can have side effects, which lead to the development of psychiatric symptoms and can worsen PNES. The only appropriate exception to using medication with PNES is if individuals present with a comorbid psychiatric condition (Oto & Reuber, 2018). Thus, PNES is usually treated through psychological therapies. Martlew et al. (2014), however, argue that there is no evidence to prove the effectiveness of any psychological and behavioural treatments for PNES, owing to the complex aetiology of the condition. To counter this, one of the very few recognised randomised clinical trials for PNES was conducted by Goldstein et al. (2010). Treatment occurred within neuropsychiatric settings where the active-treatment group received 12 sessions of CBT involving distraction, relaxation, and relapse prevention. The results showed that the treatment group experienced a significantly lower number of seizure events (Goldstein et al., 2010). Additionally, a recent meta-analysis conducted by Carlson and Perry (2017) has demonstrated that 82% of PNES individuals reduced their frequency of seizures after experiencing a form of psychotherapy, but more research is needed in order to identify effective treatments for PNES.

Treatment typically involves a multidisciplinary team consisting of neurologists, psychologists, psychiatrists, nurses, and general practitioners (Kanner, 2010). One of the barriers to treatment seen by HCPs is that patients with PNES are unable to fully accept their diagnosis (Dworetzky, 2015). Patients often feel that they are “crazy” when they are diagnosed with PNES over epilepsy. This in turn affects their willingness to attend psychological treatment (Dworetzky, 2015).

HCPs also play a role in being a barrier to treatment. It is noted that HCPs delay recognising PNES as a clinical entity, which consequently reduces the amount of attention that is paid to this condition (Baslet et al., 2015; Jafari et al., 2020). In order for PNES patients to have a good prognosis, during the initial diagnostic procedures, there needs to be proper collaboration between neurology, and fields inclusive of psychology, psychiatry, and social work (Kanner, 2010).

Another barrier is that the credibility of VEEG equipment is questioned among HCPs (Baslet et al., 2015; Kanner, 2010). Whilst neurologists strongly believe in the use of VEEG equipment for the diagnosis of PNES, many other mental health professionals such as psychiatrists or psychologists are less willing to accept the results of the VEEG for diagnostic purposes. This is mainly due to the complex aetiological nature of the condition (Baslet et al., 2015; Kanner, 2010). Therefore, a lack of communication and limited understanding in relation to diagnostic procedures for PNES is common among different HCPs, which can, in turn, affect treatment procedures (Baslet et al., 2015; Kanner, 2010).

2.8.1. Phases of Treatment

The treatment of PNES typically occurs through three phases (Baslet et al., 2015). Phase one involves a form of engagement between patients and HCPs (Baslet et al., 2015). PNES patients have a tendency to question their diagnosis, and return to their neurological physicians in order to establish the accuracy of the diagnosis presented. Within this phase, communication should be direct and clear for patients to fully understand their diagnosis (Arain et al., 2016; Baslet et al., 2015; Hall-Patch et al., 2010; Lanzillotti et al., 2021; Reuber, 2017). The end of this phase is marked by patients forming a proper understanding of their diagnosis, restraining from seeking further diagnostic confirmation, and forming a means of contact with a mental health provider (Arain et al., 2016; Baslet et al., 2015; Hall-Patch et al., 2010; Lanzillotti et al., 2021; Reuber, 2017).

The second phase of treatment entails identifying acute interventions, which include the use of both psychological and pharmacological treatments (Baslet et al., 2015; Lanzillotti et al., 2021). The objectives of such treatments are to reduce the frequency of seizures, and severity of psychiatric comorbidities. Particular attention is also paid to enhancing one’s quality of life, functional recovery, and the utilisation of medical resources (Baslet et al., 2015; Lanzilotti et al., 2021).

The third and final phase focuses on long-term interventions (Baslet et al., 2015). This is mainly for PNES individuals who still present with somatic symptoms after the acute intervention phase. Typically, these individuals have a chronic form of PNES and require ongoing care focused on functional recovery and the utilisation of medical resources (Baslet et al., 2015).

2.8.2. Different Types of Treatment

2.8.2.1. CBT. CBT presents with the most substantial body of data for its effectiveness in the treatment of PNES (LaFrance Jr et al., 2013). This therapeutic framework views PNES as a dissociative response to cognitive, physical, emotional, and environmental cues in relation to a particular distressing or life-threatening event (LaFrance Jr et al., 2013). CBT treatment therefore specifically focuses on relaxation strategies, refocusing one's attention, challenging negative cognitions, coping with avoidance behaviours, and also addressing one's personal history of possible trauma and abuse (LaFrance Jr et al., 2013).

A multicentre randomised control trial conducted by LaFrance Jr et al. (2014) has notably demonstrated the usefulness of CBT. The efficacy of CBT-informed psychotherapy, the antidepressant, sertraline, and treatment as usual for PNES, was evaluated (LaFrance Jr et al., 2014). Within this study, treatment as usual for PNES was viewed as standardised medical care where patients and their relatives, received communication about the diagnosis. Additionally, antiepileptic drugs were adjusted, and patients were referred to psychologists and psychiatrists; however, it was noted that patients were unlikely to attend psychotropic treatment (LaFrance Jr et al., 2014). The results showed that participants who received CBT-informed psychotherapy experienced a reduction in their seizures by 51.4%, and in their depressive and anxiety symptoms. They also experienced improvement in their quality of life (LaFrance Jr et al., 2014). The participants who received both CBT-informed psychotherapy and sertraline experienced a significant reduction in seizures – namely by 59.3% (LaFrance Jr et al., 2014). The participants who only received sertraline, and standardised medical care, did not demonstrate any significant reduction in their seizures (LaFrance Jr et al., 2014).

2.8.2.2. Psychodynamic Therapy. Psychodynamic theory views patients' symptoms as resulting from childhood experiences and internal processes that are often unconscious to the patient (Baslet, 2012). Any form of somatisation and dissociation is viewed as a defence mechanism to separate traumatic experiences from conscious memories (Baslet, 2012). According to psychodynamic therapy, PNES is specifically based on the assumption that individuals' symptoms are the result of their interpersonal relationships and maladaptive patterns of relating to others, developed earlier on in life (Baslet, 2012). Therapeutic techniques include tracking somatic symptoms, controlling autonomic arousal, regulating emotions and processing traumatic memories (Baslet, 2012).

There has been a limited number of studies that have specifically focused on psychodynamic treatment for PNES and that have conducted randomised control trials. The most recent study noted was conducted by De Santiago-Treviño et al. (2017). This study analysed the effectiveness of psychodynamic therapy by randomly assigning participants to a group that only received psychodynamic therapy, a group that received only CBT, and a control group that did not receive any form of psychotherapy. The frequency of PNES symptoms was reduced significantly for both psychotherapeutic interventions after three months, in comparison to the control group. There was no difference in the frequency of PNES among the two therapies used (De Santiago-Treviño et al., 2017). Participants also obtained scores of 70 after six months of psychotherapeutic treatment on the self-perception quality of life questionnaire, meaning that they had significantly improved their quality of life (De Santiago-Treviño et al., 2017).

2.8.2.3. Group Therapy. Group therapy, in comparison to psychotherapy on an individual level, is viewed as more beneficial in certain cases for PNES patients (Bullock, 2010). This is because (i) it is cost-effective, (ii) comorbid conditions can be identified among the PNES population, (iii) a ripple effect usually occurs from one patient to another in a group setting, and (iv) group members are able to obtain support from one another (Bullock, 2010).

A study by Chen et al. (2013) randomly assigned participants who had received a diagnosis of PNES into a group that received three successive and monthly group psychoeducational sessions or clinical routine seizure follow-ups, and a control group that did not receive any form of intervention. Those who received a form of group therapy were exposed to a lecture on PNES, which entailed understanding PNES signs and symptoms, safety measures to reduce the risk of harming one’s body, playing an active role in recovery, and understanding the universality of PNES as a condition shared by others (Chen et al., 2013). The results demonstrated that there was no significant difference between those who experienced psychoeducational group therapy and those in the control group. However, those who received psychoeducation showed a slight improvement in their work and social adjustment (Chen et al., 2013).

2.8.2.4. Family Therapy. Varghese et al. (2020) state that family therapy catered towards individuals with mental health is based on courtesy stigma. Courtesy stigma is where, apart from the patient, family members are exposed to stigma, and tend to be unaware and lack information about how to cope with mental illnesses (Varghese et al., 2020). Family therapy typically involves counselling and psychoeducation about the mental health condition, behavioural management, medication supervision, improving communication, and discussion about future plans (Varghese et al., 2020).

Owing to family dysfunction being a prominent factor that heightens the risk of developing PNES, and PNES being a condition that is highly stigmatised, family therapy appears to be an apparent need among PNES patients (Krawetz et al., 2001). The literature appears to be limited and only provides anecdotal support for family therapy in relation to PNES. To date, only three case studies have presented the use of family therapy for PNES.

Two of these case studies are based on a multimodal approach in relation to paediatric care (Cruz et al., 2014; Kozlowska et al., 2016), and one utilises a form of couples therapy based on the McMaster Family Functioning Model (Archambault & Ryan, 2010). These case studies show success in lessening seizure frequency and managing PNES effectively; however, larger controlled studies are required in order to determine the reliability and appropriateness of family therapy as a treatment for PNES.

2.8.2.5. Pharmacological Treatment. Often patients with PNES are provided with antiepileptic medication to stop seizures from occurring; however, there are indications that this causes a great amount of harm (LaFrance Jr & Blumer, 2010). Pharmacological treatment with individuals with PNES usually begins with tapering antiepileptic medication, followed by the prescription of other forms of medication to treat anxiety, mood, and psychotic disorders (LaFrance Jr & Blumer, 2010). The use of pharmacotherapy is effective when patients present with comorbid depression and anxiety (LaFrance Jr & Blumer, 2010).

A pilot randomised controlled trial conducted by the National Institute of Neurological Disorders and Stroke revealed that sertraline, which is typically used to treat comorbid depression, has demonstrated the ability to reduce the occurrence of seizures by 45% in PNES patients (Smith, 2014). However, due to the small pilot nature of the study, no definitive conclusions could be drawn about the use of serotonin reuptake inhibitors as treatment for PNES (Smith, 2014). Venlafaxine medication has also been associated with the treatment for PNES, resulting in patients experiencing a reduction in their seizures by over 50% (Pintor et al., 2010). Pharmacological medication is best used in addition to other treatments presented for PNES (LaFrance Jr & Blumer, 2010).

2.8.2.6. Polytherapy. As a result of the complexity of the signs and symptoms of PNES, it is important that various HCPs contribute to the diagnostic and treatment procedures of the condition (Kanner, 2010). It is vital that neurologists keep a constant form of contact with other psychological professionals in order to produce the best treatment outcome for the patient (LaFrance Jr et al., 2013). This communication is especially important if patients present with coexisting neurological abnormalities or epilepsy, as the correct amount and usage of antiepileptic drugs needs to be informed by the neurologist (LaFrance Jr et al., 2013).

As stated in the previous section, if individuals present with comorbid anxiety or mood disorders, pharmacological treatment may be required in addition to psychotherapy (LaFrance Jr & Blumer, 2010). The study by LaFrance Jr et al. (2014), which was mentioned earlier in section 2.8.2.1, showed that both CBT-informed psychotherapy and sertraline medication produced the largest amount of reduction in seizures in comparison to the two types of intervention used alone. The International League against Epilepsy stated that a multidisciplinary approach should be used for the management of PNES (Gasparini et al., 2019). This board specifically consisted of neurologists, neuropsychologists, pharmacologists, psychiatrists, experts in biomedicine, as well as patients' representatives that have thoroughly reviewed existing literature. They aimed to make informed decisions regarding the diagnostic and treatment procedures for PNES (Gasparini et al., 2019). These individuals believed that patients should be rigorously screened for mood disturbances, personality disorders, and psychic trauma; ideally CBT should be used as the first approach for treatment and then be followed by pharmacological treatment if patients present with a comorbid condition (Gasparini et al., 2019).

2.8.3. Treatment in South Africa

According to Pillay (2019), mental health is not regarded as a priority in South Africa, with only 27% of South Africans with severe mental illnesses being able to access treatment. Access to treatment is known to vary between private and public hospitals in South Africa (Naidoo & Bhigjee, 2021). In a local study by Anderson et al. (2017), patients who were able to attend an epilepsy-monitoring unit at a private hospital, were noted as receiving fundamental care, which was inclusive of services offered by neurologists, psychiatrists, and psychologists. In contrast, within South African public hospital facilities in the Western Cape, only 30% of PNES patients were able to receive psychotherapy (Pretorius & Sparrow, 2015). South African HCPs are viewed as having limited training in the identification and management of functional neurological disorders, such as PNES, which creates a barrier towards patient care, and which heightens stigma (Naidoo & Bhigjee, 2021). Additionally, there is insufficient funding for mental health services, shortages of HCPs that are able to provide psychological treatment, inadequate communication and collaboration with governmental departments, and limited management of mental health service provision (Pillay, 2019).

Furthermore, many individuals with mental illnesses in South Africa are likely to seek the services of a traditional healer over a practitioner in a hospital (Audet et al., 2017). Healers use their ability to diagnose and treat emotional or physical conditions by paying attention to causative factors such as social misconduct, spirits, and sorcery (Audet et al., 2017). Healers are more culturally sensitive to patients' needs, tend to speak patients' preferred languages, live closer, are readily available, and provide more effort in explaining the causes of illnesses, and outlining diagnostic and treatment procedures (Audet et al., 2017). Currently, there is a lack of partnership and understanding between traditional and standard medical and psychological care. It is thus suggested that more collaboration should exist between traditional and Western forms of treatment in order to heighten the well-being of patients in South Africa (Audet et al., 2017).

A study conducted on traditional healers' perceptions and experiences in delivering seizure care was conducted in a neighbouring country, Namibia (du Toit & Pretorius, 2018). The study pointed to the need for collaboration and referral systems among traditional and standardised medical care (du Toit & Pretorius, 2018). The study discovered that traditional healers identified differences in seizures by taking into consideration spiritual causes having to do with witchcraft, evil spirits, and inheritance. Treatment was in line with guidance from spiritual forces and involved ritualistic and herbal preparations (du Toit & Pretorius, 2018). The researchers of the study, du Toit and Pretorius (2018), claim that PNES is viewed as medically unexplained seizures, which in turn raises the question as to whether traditional healers can distinguish between epilepsy and PNES, and provide more culturally appropriate treatment based on spiritual beliefs. Thus, the important need for more efforts and communication to be formulated between traditional healers and other HCPs offering standard medical care, is suggested.

2.9. Level of Burden

Two important levels of burden, namely, financial and psychosocial, exist in relation to diagnostic and treatment procedures for PNES.

2.9.1. Financial Burden

When referring to financial burden, one often views it from the point of financial stressors placed on the patient in relation to healthcare centre resources and services (Ahmedani et al., 2013; Anderson et al., 2017; Magee et al., 2014; Razvi et al., 2012). In general, there is a limited amount of research on these factors in correspondence to PNES. However, a study done by Magee et al. (2014) in Ireland discovered that PNES patients experience high hospital costs amounting to € 20 995.30, which is the equivalent of R 354 969.64. This is due to the delay in reaching a correct diagnosis. Such costs were the result of patients attending outpatient neurology appointments, being treated with antiepileptic medication, visits at the emergency department, EEG recordings, computed tomography (CT), and magnetic resonance imaging (MRI) scans (Magee et al., 2014).

In the United States of America (USA), PNES healthcare patient costs were estimated to decrease from $ 4 567.01 (R 64 638.72) each year prior to receiving a diagnosis, to

$ 2 783.77 (R 39 299.81) after the confirmed PNES diagnosis was achieved (Ahmedani et al., 2013). A similar study by Razvi et al. (2012) conducted in the USA, consisted of 28 PNES patients, all of whom had encountered extremely high costs prior to diagnosis. The reason for this is because the patients had 14 home visits by a general practitioner, 31 calls to the ambulance, 34 visits at the emergency department, were admitted into hospital 21 times, and had 35 EEG recordings, 24 CT scans and eight MRI scans. It can thus be seen that a high demand is placed on medical resources by PNES patients (Razvi et al., 2012).

There are no studies in South Africa that have investigated the financial burden placed on PNES patients. The epidemiological study by Anderson et al. (2017), however, took into consideration the use of PNES central nervous system medication and antiepileptic drugs. The study found that there was a significant reduction in the use of such medication post-diagnosis, potentially meaning that the financial burden would decrease for patients after obtaining a correct diagnosis.

It is essential to note that most studies conducted on financial burden were in well-resourced countries where there tends to be more access to equipment and support funds. Access to resources in developing countries such as South Africa is usually limited (Gaede & Versteeg, 2011). Expenditure dedicated to mental health in South Africa only accounts for 5.0% of the total health budget, meaning that not enough recognition and quality care is provided to people with mental illnesses (Docrat et al., 2019). This also suggests that the financial burden for PNES patients in South Africa may be much higher, especially if a patient were to lose their job as a result of having a disability like PNES.

The most likely reason for PNES individuals experiencing job losses is due to the high stigmatisation associated with the condition (Pretorius & Sparrow, 2015). Many people who have PNES are viewed as engaging in a form of malingering, faking their seizures, or having control over their behaviour (Pretorius & Sparrow, 2015), and thus tend to be viewed as incapable of upholding a professional etiquette. Owing to the limited support funds offered to patients after job loss, PNES patients still face the financial stress of having to provide for themselves and potential family members (Asadi-Pooya & Bazrafshan, 2020). They are also likely to experience difficulties in obtaining new job opportunities due to employers being discriminatory and fearing seizure episodes in the workplace (Asadi-Pooya & Bazrafshan, 2020). Financial stress also increases PNES individuals' risk of developing other psychiatric conditions such as anxiety and depression, which in turn leads to treatment plans becoming unaffordable, apart from the already expensive VEEG diagnostic procedures and psychotherapeutic treatment for PNES (Asadi-Pooya & Bazrafshan, 2020).

Furthermore, those individuals who are perceived to have limited financial resources are often viewed as inferior, lazy, unmotivated, and incapable of taking responsibility (Simons et al., 2018). As a result of such stigmatising attitudes held by society in general, including HCPs, individuals with a low-income earning potential tend to be viewed as less deserving of care (Simons et al., 2018). Owing to this, patients are less likely to attend diagnostic procedures and are more likely avoid "superior figures" like HCPs, which may consequently increase financial burden due to delay in achieving a correct diagnosis (Robson & Lian, 2017; Simons et al., 2018).

2.9.2. Psychosocial Burden

Patients with PNES experience a great level of psychosocial burden, owing specifically to the amount of stigma that they face. Studies that significantly demonstrate this were conducted by Carton et al. (2003) and Rawlings and Reuber (2016). The study by Carton et al. (2003) investigated PNES patients' reactions to obtaining and understanding their diagnosis. The study by Rawlings and Reuber (2016) explored how patients with PNES live with their condition. The researchers discovered that participants faced a form of social isolation, had challenges in gaining employment, did not necessarily have positive encounters with HCPs, experienced a decrease in their self-esteem and confidence, and had worries about the future (Carton et al., 2003; Rawlings & Reuber, 2016). Additionally, the participants experienced a reduction in their quality of life (Carton et al., 2003; Rawlings & Reuber, 2016). This will be explained in more detail below in correspondence with other research.

2.9.2.1. Quality of Life. Most studies determine the prognosis and outcome of PNES patients by observing their reduction in seizure frequency (Farias et al., 2003; McKenzie et al., 2016). However, some researchers claim that this is not always the best way to measure improvements in the patient group. For example, a study by LaFrance Jr and Syc (2009), demonstrated that a person's quality of life would worsen if they had high scores for depressive and somatic symptoms, rather than seizure frequency. A similar study by Szaflarski et al. (2003) showed that PNES patients, in comparison to epilepsy patients, experienced a lower health-related quality of life owing to having increased depressive symptoms, and experiencing the negative side effects of antiepileptic medication, thus, demonstrating again the importance of obtaining an early accurate diagnosis.

Furthermore, a study by Nemade et al. (2020) showed that PNES individuals who have a lower level of education, limited family support or conflicts (such as patients in the family being treated with extra precaution or family members feeling that they are helpless and cannot assist), and that were unemployed and experienced grief due to no longer having a sense of responsibility, were likely to experience an increased level of burden and worse-off prognosis.

The only study to be conducted on the health-related quality of PNES patients in South Africa is by Cronje and Pretorius (2013). In this study, PNES patients' health-related quality of life scores were compared to a healthy control group. The PNES group had a significantly lower score, particularly displaying avoidance and distance coping strategies, which had a negative influence on their quality of life (Cronje & Pretorius, 2013).

All of the studies demonstrated the significance of taking into consideration the quality of life for patients in order to determine the level of burden experienced and the outcome for patients.

2.10. Prognosis/Outcome

There is a limited amount of literature on the prognosis of PNES. Most studies were conducted before the year 2010. From these studies, the prognosis for PNES tends to be viewed as poor, with 25-80% of PNES patients either experiencing a form of constant seizures or seizure relapse (Farias et al., 2003; O'Sullivan et al., 2006; Reuber et al., 2003; Reuber & House, 2002). Concurrently, seizure cessation was displayed by 16-58% of patients, with follow-up procedures demonstrating that 25-40% of patients experienced seizure reduction (Duncan et al., 2016; Ettinger et al., 1999; McKenzie et al., 2010; McKenzie et al., 2016; O'Sullivan et al., 2007; Sadan et al., 2016). Determining the prognosis of PNES is highly complex and problematic, due to patients differing in psychological processes and social factors that serve as a predictor of one's outcome (Bodde et al., 2009b).

There are various factors that have an influence on the prognosis of PNES (Durrant et al., 2011). An individual's age of onset affects the ability of one to achieve a better prognosis; children who are diagnosed at an early stage are likely to have a better outcome in comparison to older adults (Durrant et al., 2011; Reuber et al., 2003). Gender is also likely to play a role, but requires further investigation (Durrant et al., 2011). McKenzie et al. (2010) found that males were more likely to experience seizure remission after follow-ups were conducted. Furthermore, socio-economic factors, such as having a higher education status and being employed upon receiving the diagnosis of PNES, resulted in lower seizure remission rates (Arain et al., 2007; Carton et al., 2003).

Carton et al. (2003) discovered that patients who accepted their diagnosis and felt relieved about not having epilepsy had a better outcome than patients who reacted with anger and confusion. Additionally, if an individual is able to live an independent life, and form and maintain relationships, they are likely to be seizure-free (Silva et al., 2001). The types of seizures that patients have can also affect prognosis outcomes. Individuals who have catatonic seizures, which are recognised as seizures that occur for an extended period of time without any display of motion and response, are likely to experience a better outcome (Arrain et al., 2007; Selwa et al., 2000). Individuals that present with comorbid anxiety, depression and epilepsy, tend to have a predisposition for frequent seizure episodes; thus, resulting in them having a poorer outcome (Bodde et al., 2007; Durrant et al., 2011; Reuber et al., 2003).

The communication of the diagnosis of PNES has a significant influence on patients' outcomes in relation to reducing symptoms and promoting the uptake of treatment (Hartwig & Pretorius, 2019). Communication begins with a HCP and involves providing detailed information about PNES in an understandable manner, providing validation for patients' symptoms, and being empathic (Fouché et al., 2019; Hartwig & Pretorius, 2019). If HCPs show genuine attentiveness towards their patients, they are also able to reduce their patients' level of uncertainty and experience of stigma (Fouché et al., 2019; Hartwig & Pretorius, 2019). The aim of this current study is to explore HCPs' stigma towards people with PNES. The next section will specifically focus on PNES patients' experiences of stigma from HCPs.

2.11. PNES Patients' Experiences of Stigma from HCPs

Whilst PNES patients face a great number of challenges, including the complex aetiology of the condition, difficulties with diagnostic and treatment procedures, and financial and psychosocial burden, possibly the biggest problem that they encounter is stigma, especially from HCPs. Owing to the focus of this study being on HCPs and their stigma towards people with PNES, and in order to create a holistic point of view, it is important to formulate an understanding from the patients' perspective regarding how they feel they have been stigmatised by HCPs. However, it must be noted that literature on PNES is limited, with stigma in relation to the condition being hardly investigated. From the existing identified literature, the patients commonly experienced scepticism, humiliation and discrimination, social isolation, and misdiagnoses from HCPs, all of which will be elaborated on below.

2.11.1. Scepticism

When interacting with HCPs, PNES patients described their experience as one where they were not taken seriously, and their symptoms were met with doubt and disbelief

(Robson et al., 2018). Patients were often spoken to in a demeaning manner owing to the lack of awareness that HCPs have about PNES; in the study by Tolchin et al. (2016, p. 26), one patient stated that they were told to “man up” because they had seizures that were caused psychologically.

Additionally, many patients stated that their HCPs believed that they were engaging in a form of malingering. Malingering refers to purposefully producing fake symptoms in order to achieve a form of secondary gain (Robson & Lian, 2017). Many patients were told that they were attention-seeking, and exhibiting health-seeking behaviour to avoid work (Robson & Lian, 2017). HCPs also reinforced the idea of patients faking their symptoms by having private conversations with family members to address such allegations (Tolchin et al., 2016). Patients state that they are often blamed for their condition, and are viewed as having the ability to control their seizures (Robson & Lian, 2017). As a result of the frequent scepticism displayed by HCPs, patients have in turn started to doubt their own symptoms and have avoided returning to follow-up procedures (Rawlings & Reuber, 2016). Thus, it is noted that both patients and HCPs experience scepticism around the diagnosis of PNES.

2.11.2. Humiliation and Discrimination

Patients frequently experience stigma from HCPs through the use of stereotypes such as that people with mental health conditions are “crazy” and “time-wasters”, with the root of discrimination being linked to having an underlying psychological condition (Rawlings et al., 2018). PNES patients state that they are often viewed as being less deserving of care due to PNES not being regarding as a clinical entity by HCPs (Dimaro et al., 2015; Pretorius & Sparrow, 2015; Rawlings et al., 2017; Rawlings & Reuber, 2016; Robson et al., 2018; Robson & Lian, 2017; Tolchin et al., 2016).

Patients view themselves as outcasts because of having seizures that are caused by psychological trauma, and HCPs specifically choosing to focus on what PNES patients do not have in relation to epilepsy patients (Robson & Lian, 2017). Many HCPs discriminate against PNES patients by not actively listening to their patients’ subjective experiences; for example, one patient stated that the HCP viewed her concerns as “funny turns that would go away eventually by themselves” (Robson & Lian, 2017, p. 8). Owing to such experiences, PNES patients were regarded as having higher levels of perceived stigma (holding a fear of being discriminated against, and internalising perceived discriminatory thoughts), than those who have a medical condition where the pathological pathway is clearly identifiable (Rawlings et al., 2018). A recent study conducted by Karakis et al. (2020), consisting of 43 PNES patients, and 165 epilepsy patients, found that PNES patients experienced a greater degree of stigma in comparison to epilepsy patients (76.5% versus 59.5%), which is associated with negative quality of life outcomes.

Furthermore, in extreme cases, humiliation and discrimination may involve physical assault. In the study by Robson and Lian (2017, p. 9), one patient referred to a traumatic experience where they stated: "The nurse […] put me in a wheelchair with force and started shouting at me and pushing my shoulder and head back into the chair". PNES patients report experiencing unjust care by HCPs, which can result in poor and painful consequences.

2.11.3. Social Isolation

Social isolation refers to how patients feel alone and without support. Many HCPs were viewed as not providing an adequate amount of support to their patients, and would only see their patients for a limited amount of time; thus, resulting in the patients feeling isolated (Pretorius & Sparrow, 2015; Robson & Lian, 2017). Consequently, patients developed a lower motivation to pursue treatment avenues, and became withdrawn and hardly spoke about their illness (Rawlings & Reuber, 2016). Social isolation is therefore viewed as a negative effect of stigma, resulting in many patients developing a sense of hopelessness and lack of trust in HCPs (Whitehead et al., 2013).

2.11.4. Misdiagnosis

Owing to the complexity of symptoms displayed by PNES patients, the condition is often mistaken for epilepsy. As a result, patients report being misdiagnosed and inappropriately treated with harmful antiepileptic medication for a vast number of years (Rawlings et al., 2017). When a patient is identified as having PNES, they are often faced with feelings of fraud, anger, and confusion by HCPs (Rawlings & Reuber, 2016). Subsequently, patients tend to develop a low self-esteem due to not being provided with appropriate services by HCPs, where they are able to demonstrate a proper understanding of the condition (Dimaro et al., 2015). It can therefore be seen that being unable to provide an accurate diagnosis of PNES, and demonstrating a lack of knowledge, is one of the many ways in which patients with PNES perceive HCPs to be stigmatising.

2.12. HCPs' Perspectives of their Stigma towards People with Mental Illnesses and PNES

The relationship between a HCP and patient is of essence to ensure the best outcome in relation to patients' safety, health, and resource use (Robson & Lian, 2017). PNES is noted as a complex condition to diagnose and treat, which in turn affects how HCPs work with patients. Many HCPs describe their experiences with PNES patients as being difficult, frustrating, confusing, and uncomfortable (Robson & Lian, 2017). These negative attitudes are often the result of their limited training and understanding of PNES. Owing to such complications, HCPs often develop extreme levels of stigma towards their patients (Robson & Lian, 2017). Due to the focus of this study being on HCPs' stigma towards people with PNES, it is important to describe the HCPs' perspectives.

Literature based on stigma and PNES, especially in relation to the HCPs' point of view, is limited (Annandale et al., 2022). In order to add to the discussion of stigma and HCPs' perspectives, articles based on HCPs' stigma towards mental illnesses in general, were also taken into consideration to allow for a thorough discussion. HCPs' perspectives of stigma towards people with mental illnesses and PNES were mainly related to diagnostic terms used, the diagnosis of mental illnesses and PNES, treatment and management, and HCPs having inherent stigmatising attitudes. These factors will be discussed in more depth below.

2.12.1. Diagnostic Terms

Diagnostic terms are based on the HCPs' comfortableness with terms that are used to refer to PNES. HCPs' uncertainty with PNES could be seen in their inability to agree on a term. In certain instances, some terms were considered to be inappropriate and reflected HCPs' stigmatising beliefs. The preference of diagnostic terms used by HCPs are acknowledged by them as a form of stigma, as it discredited patients' symptoms and labelled them as having an undesirable trait (Rawlings & Reuber, 2018; Sahaya et al., 2012; Yogarajah et al., 2019).

From the literature reviewed, it can be seen that although most HCPs preferred neutral terms such as non-epileptic seizures, a majority of them still used terms such as "fake seizures" or "hysterical seizures" (Sahaya et al., 2012, p. 1306). "Pseudoseizures" (Rawlings & Reuber, 2018; Yogarajah et al., 2019, p. 57) were identified as the preferred term used by neurologists and epileptologists. These diagnostic labels indicate that an individual differs from the norm, which in itself is stigmatising, due to it being offensive and serving as confirmation that patients' symptoms are not real. Such terms were therefore inappropriate, resulted in humiliation, and did not provide a sense of validity to the seriousness of patients' symptoms (Rawlings & Reuber, 2018; Sahaya et al., 2012; Yogarajah et al., 2019).

Additionally, it was noted that HCPs tend to use dualistic terms associated with PNES; this results in the incorrect labelling of a patient. Particularly, Rawlings and Reuber (2018, p. 1112) identified that HCPs typically used terms such as "nonepiletpic seizures", "nonepileptic attacks", and "nonepileptic attack disorder", and whilst those were accepted, it was still perceived as stigmatising because it stated what a person lacks. This is because the condition is undermined owing to the term beginning with “non”, and only serving as a recognition that a patient does not have epilepsy. Therefore, it also demonstrates that HCPs prefer to see symptoms that can be measured easily and that are well-known, such as in the case of epilepsy (Rawlings & Reuber, 2018).

From the findings it can be seen that those terms beginning with “non-epileptic”, as well as the terms “pseudoseizures” and “fake seizures”, were preferred by HCPs. These terms were viewed as highly stigmatising as it suggested that patients’ symptoms were of a false nature.

2.12.2. Diagnosis

HCPs are often unaware of the exact diagnosis of mental illnesses and PNES. This mainly relates to their lack of experience and understanding of symptoms, as well as frustration with providing a diagnosis to patients. PNES can be a difficult disorder to diagnose and it often takes years to arrive at an accurate diagnosis. As a result of the complexity of this condition, there is a high tendency for a misdiagnosis to occur, with symptoms being perceived as a form of epilepsy, or patients displaying a sense of malingering (du Toit & Pretorius, 2017; McMillan et al., 2014; Rawlings & Reuber, 2018; Rivera-Segarra et al., 2019; Sahaya et al., 2012; Yogarajah et al., 2019).

In various studies, HCPs were regarded as having a lack of understanding about the symptoms presented by patients with mental illnesses or PNES (McMillan et al., 2014; Rivera-Segarra et al., 2019). As a result, they often believed their patients to be faking their symptoms. They also viewed their patients as wanting attention or a means of secondary gain (McMillan et al., 2014; Rivera-Segarra et al., 2019). Some HCPs recognised that they were stigmatising in that they sometimes believed that, owing to their own negative attitudes, they perceived patients with PNES to have symptoms that were “too convenient” (McMillan et al., 2014, p. 278). Due to HCPs perceiving their patients’ symptoms to not be “real”, and generally lacking knowledge, it was noted that the diagnosis given to patients was one that did not provide them with a proper account for their condition, and which led to them being neglected by their primary HCP (Rivera-Segarra et al., 2019).

In addition, Yogarajah et al. (2019) specifically discovered that GPs were unsure about whether PNES was voluntarily controlled. Approximately 31% of GPs believed that patients were faking their symptoms. Most GPs thought that seizures did not only occur when patients were stressed (Yogarajah et al., 2019). Thus, due to not being aware of the exact symptoms of PNES and not knowing how to identify symptoms that were voluntarily controlled, it led to further complications in the diagnosis. GPs experienced frustration due to their own limited knowledge, and because of this they preferred to label patients as having fake symptoms instead of providing them with a proper diagnosis (Yogarajah et al., 2019). This is stigmatising, as it is perceived that the patients' symptoms were not valid and worthy of consideration for diagnostic purposes.

Furthermore, the HCPs' lack of knowledge was seen in how they would engage in certain practices (Rawlings & Reuber, 2018). Rawlings and Reuber (2018, p. 1118) identified that when HCPs would communicate their diagnosis to patients, they would often start off by saying "I think", thus, demonstrating their limited knowledge. In reports about their patients, they were seen to use ambiguous language. Many HCPs also made their diagnosis by placing bets on what they thought the most likely option was (Rawlings & Reuber, 2018).

Additionally, it was discovered that as a result of HCPs' uncertainty about the diagnosis of PNES, they felt more comfortable treating patients with epilepsy (du Toit & Pretorius, 2017; Rawlings & Reuber, 2018). Their lack of knowledge and experience with PNES prevented them from further caring for PNES patients, to the point where they would only focus on physical elements of the condition which resembled that of epilepsy rather than those which were psychological (du Toit & Pretorius, 2017; Rawlings & Reuber, 2018).

Moreover, PNES often presents comorbidly with epilepsy (Rawlings & Reuber, 2018). Sartorious (2013) claims that with comorbid conditions, HCPs tend to focus on the condition which is likely physical, as they have more knowledge about it and prefer to treat it, which in turn undermines the importance of any mental condition that is present. HCPs often proceed with a single-disease treatment in the hope that other psychological symptoms will disappear after the physical symptoms have been treated (Sartorious, 2013).

Furthermore, du Toit and Pretorius (2017) stated that owing to PNES being a fairly new condition for HCPs to diagnose, many of them felt frustrated and in turn their stigmatising beliefs were enhanced (du Toit & Pretorius, 2017). HCPs also expressed that the diagnosis was difficult because they perceived their patients to be reluctant in accepting the information provided. This subsequently resulted in HCPs being less willing to help (du Toit & Pretorius, 2017). HCPs also reported that the condition was too costly and time-consuming to manage; however, some HCPs were also reluctant to diagnose patients, even when the proper equipment was provided to them such as EEG monitoring (du Toit & Pretorius, 2017). The same was found in a study by Sahaya et al. (2012) as HCPs believed that VEEG equipment was not necessary for the diagnosis of PNES. Again, the HCPs believed PNES to be in voluntary control, implying that the symptoms were "fake" (Sahaya et al., 2012, p.

1305). Within this specific study (Sahaya et al., 2018), due to the survey gaining a low response rate, the researchers of the study believed that non-respondents felt that PNES should not be considered a diagnostic entity.

Thus, it can be seen that the majority of HCPs had a lack of understanding of PNES and believed that there was a component of "faking" or voluntary control to this condition.

2.12.3. Treatment and Management

Treatment and management offer a description of what HCPs believed was the best treatment for their patients, services that were available, as well as a reflection on how comfortable HCPs were when treating their patients. The HCPs appeared to treat their patients in a stigmatising manner, as seen in the relevant studies identified (du Toit & Pretorius, 2017; Knaak et al., 2017; McMillan et al., 2014; Rawlings & Reuber, 2018; Rivera-Segarra et al., 2019; Tolchin et al., 2016; Ubaka et al., 2018; Yogarajah et al., 2019).

Knaak et al. (2017) and Rivera-Segarra et al. (2019) interpreted HCPs as having a pessimistic attitude about the recovery of their patients with a serious mental disorder, due to their lack of skills. Pessimism resulted in HCPs feeling helpless and believing that no matter what they do, it would not be effective (Knaak et al., 2017). For instance, they described patients as being "not curable" (Rivera-Segarra et al., 2019, p. 8) even when exposed to therapy or medication. The HCPs' inadequate skills and training were linked to stigma in two ways. The first was that a lack of skills resulted in there being fear and anxiety, which led to avoidance and clinical resistance of patients (Knaak et al., 2017). Secondly, treatment was inadequate and resulted in poor provider-patient interactions, and negative outcomes overall (Knaak et al., 2017).

Additionally, in certain institutional cultures, and society at large, having a mental illness was regarded as shameful (Rivera-Segarra et al., 2018). Therefore, association with such individuals was also negatively looked down upon, which in turn led to HCPs being dismissive or avoidant of their patients. In specific occurrences, this was seen as detrimental as it led to patients not feeling comfortable enough to disclose information and did not allow for proper treatment (Rivera-Segarra et al., 2018). Ubaka et al. (2018) found that many patients with mental illnesses were excluded and feared by HCPs. Patients were regarded as unable to be trusted and were also feared because they were believed to be contagious. Due to such negative beliefs, there was a continued lack of space for patient counselling and resistance by physicians to implementing care interventions (Ubaka et al., 2018).

Furthermore, McMillan et al. (2014) discovered that patients with PNES were described as difficult to treat, unable to benefit from help, and being overall hopeless, which in turn made clinicians feel frustrated. Many clinicians indicated that they were not interested in PNES, and that there were only a few good options to treat the condition (McMillan et al., 2014). Clinicians also reported that patients were not always welcomed in neurology and mental health clinics as they did not feel comfortable treating them (McMillan et al., 2014).

Tolchin et al. (2016) declared that due to the difficulty in diagnosing PNES, the symptoms were seen as too complex to treat. HCPs had a lack of skills to address patients properly, and also spoke to them in a demeaning manner. HCPs also commonly made jokes about PNES, such as, “doctor has a pseudoseizure to avoid seeing patient with pseuodseizures” (Tolchin et al., 2016, p. 26). Such jokes often led to them being dismissive in their treatment (Tolchin et al., 2016).

The study done by du Toit and Pretorius (2017) was one in which HCPs reported on using CBT to treat patients and expressing that PNES was difficult to treat. If patients did not respond properly to CBT the first time, this inevitably left HCPs with fatigue and frustration, and reinforced their beliefs that patients were faking their symptoms. Thus, some HCPs believed that psychotherapy was an ineffective treatment (du Toit & Pretorius, 2017).

Rawlings and Reuber (2018) also noted that HCPs affirmed that treating patients with PNES was difficult and time-consuming, and that these patients were “beyond help” (Rawlings & Reuber, 2018, p. 1119). When patients failed to respond to treatment, this would result in HCPs becoming exhausted and believing that patients were faking their symptoms (Rawlings & Reuber, 2018). One HCP that was interviewed stated that some HCPs call pastors to pray for PNES patients as it is believed that these patients are possessed by demons. This is a deeply held cultural belief, which could be interpreted as stigmatising by patients (Rawlings & Reuber, 2018). Additionally, neurologists believed that treating patients with PNES was not their responsibility. In specific occurrences, other HCPs did not make a referral to specialists for their patients, and told their patients to book an appointment themselves (Rawlings & Reuber, 2018). HCPs explained that their negative attitudes can lead to misdiagnosis, stigmatisation, and patients failing to seek treatment (Rawlings & Reuber, 2018).

Additionally, in relation to referring patients, Yogarajah et al. (2019) found that the majority of GPs felt uncomfortable referring patients to psychiatry. Sartorious (2013) claims that HCPs, in general, tend to avoid making referrals for patients to mental healthcare owing to the fear of the perceived stigmatisation they may experience for working with individuals with mental illnesses. Furthermore, sending patients to specialised care which differentiated them from others could also potentially result in stigma (Nyblade et al., 2019).

From the above-mentioned information, it can be noted that many HCPs perceive mental illnesses and PNES as conditions with high complexity, and consequently develop stigma towards their patients. Owing to these negative beliefs, they become ineffective in their treatment.

2.12.4. Stigmatising Attitudes

Stigmatising attitudes is based on actual accounts of stigma by HCPs. These accounts are viewed as highly significant, owing to the focus of this study. Attitudes in this instance refer to perceptions and beliefs that HCPs hold about patients with mental illnesses and/or PNES. In certain cases, these attitudes were seen as stigmatising and led to negative behaviours which were displayed by HCPs. Possible reasons for HCPs being stigmatising were also discovered and will be discussed further (du Toit & Pretorius, 2017; Helmus et al., 2019; Knaak et al., 2017; Kohrt et al., 2020; McMillan et al., 2014; Nyblade et al., 2019; Rawlings & Reuber, 2018; Rivera-Segarra et al., 2019; Tolchin et al., 2016; Ubaka et al., 2018; Vaccari et al., 2020).

It has been observed in multiple studies that patients with mental illnesses often had to deal with an intergroup bias. This was because they were continuously stigmatised and feared by HCPs, due to being potentially dangerous and incompetent (Helmus et al., 2019; Kohrt et al., 2020; Nyblade et al., 2019; Rivera-Segarra et al., 2019; Ubaka et al., 2018). Some HCPs reported feeling scared of their mentally ill patients, even after these patients were noted as stabilised (Kohrt et al., 2020). There was a perception that patients would hurt the HCPs. Knaak et al. (2017) reported that patients were often devalued, dehumanised, and dismissed by HCPs. Stigmatising attitudes and behaviours were consistent across the healthcare system. Patients specifically with mental illnesses were regarded as less deserving of care as they were perceived to be difficult and manipulative by HCPs (Knaak et al., 2017). In the workplace context, HCPs held the view that individuals with mental illnesses were unpredictable. This in turn influenced stigmatising attitudes and preferences for social distance (Knaak et al., 2017).

Additionally, some HCPs held the stigmatising attitude that their patients were “mad”, and they also believed that talking to them was of no use because “they were out of their mind” (Kohrt et al., 2020, p. 7). In some situations, it was believed that patients were inferior and should be treated coercively. Mental health hospitals were regarded as out-dated and of no need to treat patients (Ubaka et al., 2018). Patients were also often regarded as being not useful to society, and were seen as incapable of taking responsibility for their problems (Helmus et al., 2019). Many HCPs stated that they experienced moral distress based on their personal disapproval of behaviours, which in turn led to them developing negative attitudes that prevented them from providing quality care (Kohrt et al., 2020).

HCPs also tended to show a pattern of labelling, stereotyping, and discrimination, which overtly expressed their negative attitudes. For example, Rivera-Segarra et al. (2019) stated that HCPs regarded patients with a serious mental illness as social outliers. They negatively perceived their patients to be living in rural areas. This identification was used to "make fun of" those from low socio-economic status and low education backgrounds (Rivera-Segarra et al., 2019). They also further stigmatised their patients by labelling them as "crazy" (Rivera-Segarra et al., 2018, p. 8), due to needing psychiatric care.

Vaccari et al. (2020) similarly expressed that HCPs have the tendency to be negative, rigid, and totalitarian. They labelled patients in a joking manner because they believed that they were exaggerating their symptoms. They viewed their patients to be victimising themselves, and continuously referred to them as "not normal" or "crazy" (Vaccari et al., 2020, p. 7). In addition, HCPs sometimes treated people diagnosed with a serious mental disorder with a defensive attitude and minimised their health symptoms. This showed that HCPs believed that their patients were unworthy of their care and trying to obtain a means of secondary gain (Vaccari et al., 2020).

The same beliefs held by those HCPs about mental illnesses, were also true in relation to beliefs held about PNES patients by other HCPs (Tolchin et al., 2016). PNES patients were noted as frequently causing frustration for HCPs in general, and were also believed to be taking away time from those with "real symptoms" that actually matter (Tolchin et al., 2016, p. 26). Additionally, HCPs had the tendency to believe that PNES patients would consciously fake their symptoms to avoid difficult experiences, and in turn labelled them as "crazy" (Tolchin et al., 2016, p. 26).

Similarly, McMillan et al. (2014) expressed that HCPs believed that patients only presented with PNES because they could gain disability compensation. Many HCPs thought that patients declined VEEG monitoring because it was perceived that if the truth was revealed, they would no longer obtain benefits; the same was discovered by Rawlings and Reuber (2018). du Toit and Pretorius (2017) also stated that in certain instances, HCPs perceived their patients to be faking their seizures for means of secondary gain such as to avoid their current responsibilities, secure family support, malingering or some other ulterior motive.

Furthermore, Tolchin et al. (2016) revealed that many ethical codes were violated by HCPs when dealing with PNES patients. The ethical principle of nonmaleficence was violated as HCPs often demonstrated mockery towards patients with PNES and undermined their diagnosis. The principles of autonomy and justice were also violated, as patients tended to not be treated with respect and were seen as a means of amusement to HCPs (Tolchin et al., 2016).

In specific instances, HCPs mentioned that they were unaware of how stigma manifests. This resulted in them being blind-sighted to their own stigmatising actions, and health policies, facilities, and structures that may also be stigmatising (Nyblade et al., 2019). Moreover, it was also noted that people with mental illnesses experience stigmatisation in healthcare facilities to the same extent as that of the general population (Helmus et al., 2019). HCPs often see themselves as superior to their patients with mental illnesses. This leads to a categorisation of “us” being the HCPs versus “them” which are the patients (Helmus et al., 2019). It is thus recognised that only when HCPs are provided with anti-stigma training, do they become more willing and able to realise their own beliefs (Knaak et al., 2017).

Therefore, it can be seen that due to HCPs holding negative attitudes towards people with mental illnesses and PNES, they displayed various forms of stigma towards their patients such as using negative labels, avoiding and fearing patients, and believing that patients were seeking a form of secondary gain.

2.13. Chapter Summary

In this chapter, I provided a detailed discussion about the relevant literature that is available on PNES. PNES nosology, historical background, signs and symptoms, epidemiology, and aetiology and risk factors, were discussed. Following this, was a discussion on the diagnosis, treatment, level of burden, and prognosis and outcome for PNES patients. The PNES patients’ experience of stigma from HCPs was also provided and elaborated on. Finally, I closed the chapter by focusing on HCPs’ perspectives of their stigma towards people with mental illnesses and PNES. In the next chapter, I provide a discussion of the theoretical framework that will be used to analyse my findings of the research.

Chapter 3: Theoretical Framework

3.1. Introduction

As one of the main objectives of this study is to explore HCPs' views of how their stigma manifests towards people with PNES, The Health Stigma and Discrimination Framework, formulated by Stangl et al. (2019), will be utilised to conceptualise my study. According to this framework, the process of stigmatisation is complex and evolves through a socio-ecological spectrum within the context of healthcare. This particular process is characterised by various domains including drivers and facilitators, stigma marking, manifestations, and outcomes which are evident in the affected populations (Stangl et al., 2019).

This theoretical framework specifically takes into consideration that stigma serves as a hinderance towards mental healthcare services, involving genuine care outcomes and treatment advocacy (Stangl et al., 2019). Therefore, it is deemed the most appropriate to discover HCPs' stigma towards people with PNES. It also provides an understanding of how racial and economic ramifications intersect with health-related stigma (Stangl et al., 2019), thus, making it useful within a South African context. HCPs' stigma towards people with PNES will be explored through this process of stigmatisation and the distinct domains mentioned in the framework. This is elaborated on, in chapters five and six. Specifically, the framework will be used both deductively and inductively, to code the individual interviews and draw conclusions which can be related to the theory.

3.2. The Health Stigma and Discrimination Framework

The Health Stigma and Discrimination Framework (depicted in Figure 2) views stigmatisation as unfolding within the context of healthcare through a socio-ecological spectrum, which may vary according to the economic status of a country (Stangl et al., 2019). South Africa is recognised as an upper-middle-income country with limited resources, which may in turn affect diagnostic and treatment processes, and thereby could affect the development of stigma (Egbe et al., 2014; The World Bank Group, 2021). According to this framework, the process of stigmatisation begins with drivers and facilitators which are based on attitudes, norms, education, and policies (Stangl et al., 2019). This is followed by stigma marking, which involves stigma directed towards a specific health condition, as well as interrelated stigmas having to do with race and social class (Stangl et al., 2019). Thereafter, stigmatising experiences and practices are explored in more detail (Stangl et al., 2019). The final process involves examining outcomes related to rightful healthcare procedures, laws, and social protections (Stangl et al., 2019). These processes will be explored further.

3.2.1. Drivers

The first domain of the stigmatisation process involves drivers. Drivers refer to factors that enhance health-related stigma and are always viewed as negative. They include lack of awareness, fear of infections, economic ramifications, and stereotypical prejudices (Stangl et al., 2019). Social judgement and blame are evident in this process, which in turn raise concerns around the productivity of services (Stangl et al., 2019). In this study, drivers can possibly refer to the inherent fear HCPs have about contracting PNES, or HCPs being unwilling to be productive as the condition is considered “pointless” to treat, due to their own relative limited knowledge (McMillan et al., 2014).

3.2.2. Facilitators

The second domain is facilitators, which can be regarded as either having a positive or negative influence (Stangl et al., 2019). It has been recognised that stigmatising behaviours may be limited or exacerbated, depending on the absence or presence of occupational safety standards and protection strategies. This also includes factors related to equality, as well as cultural, social, and gender norms (Stangl et al., 2019). A social and hospital cultural norm held by HCPs is that they tend to believe that individuals with PNES are faking their seizures, which can be viewed as a stigmatising and negative facilitator (Sahaya et al., 2012). A way in which a facilitator can possibly be seen as positive is if a healthcare policy emphasises education programmes and anti-stigma training for HCPs (Knaak et al., 2017).

3.2.3. Stigma Marking

Both drivers and facilitators determine whether stigma marking unfolds. Stigma marking refers to a form of stigma that is applied to an individual or groups of individuals based on their health condition (Stangl et al., 2019). In this case, it is stigma that is directed towards individuals who have the mental health condition, PNES. Intersecting stigmas are also recognised within this domain (Stangl et al., 2019). Individuals who have a perceived difference having to do with race, gender, sexual orientation, occupational qualification, and social class, may experience different, as well as heightened forms of stigma (Stangl et al., 2019). It is noted that within South Africa especially, most individuals are only able to afford public healthcare rather than private healthcare (Mhlanga & Garidzirai, 2020). Private healthcare settings tend to have more resources such as that of VEEG equipment, which results in effective diagnostic procedures, and in turn may reduce the levels of stigma experienced. Thus, it is expected that individuals who can only afford public healthcare may experience increased levels of stigma and discrimination (Brown et al., 2011; Mhlanga & Garidzirai, 2020).

3.2.4. Manifestations

Manifestations follow stigma marking. This process is split into stigmatising experiences and stigmatising practices (Stangl et al., 2019). Stigmatising experiences refer to stigmatising behaviours that occur within the scope of law such as stating that individuals with PNES may not be allowed to drive or work, as well as stigmatising behaviours that occur outside the scope of law such as possible verbal abuses used by HCPs (Stangl et al., 2019; Tolchin et al., 2016). Stigmatising experiences also include internalised stigma, where an individual internalises perceived discriminatory thoughts (Stangl et al., 2019). For example, individuals with PNES may start to believe that their condition is not an authentic clinical entity as a result of negative comments shared by HCPs (Sahaya et al., 2012). Perceived stigma is also recognised, and is based on the perspective of how a stigmatised group is likely to be treated within a specific context (Stangl et al., 2019). A potential perception held is that patients with PNES will be misdiagnosed with epilepsy within a healthcare setting due to HCPs not having an adequate amount of training (Pretorius, 2016).

Anticipated stigma, the expectation that individuals will experience a form of stigma if they share their health condition with others, is also included (Stangl et al., 2019). Therefore, if patients state that they have seizures that are caused psychologically rather than physiologically, they may experience a type of stigma, such as that they are engaging in a form of malingering (Pretorius & Sparrow, 2015). Additionally, associated stigma is included; it entails being stigmatised due to having a connection with an individual because of their condition (Stangl et al., 2019). Thus, HCPs may be negatively looked down upon for working with individuals with PNES.

Furthermore, stigmatising practices refer to stereotypes that are widely held, but which are oversimplified beliefs, and prejudices that are preconceived negative evaluations not based on facts. This also includes inappropriate behaviours or discriminatory attitudes (Stangl et al., 2019). PNES patients are often stereotyped as being “crazy”, and experience inappropriate and unnecessary referrals by HCPs to other healthcare services, due to being perceived as a “waste of time” (Robson & Lian, 2017). Stereotypes and prejudices are specifically mentioned under the headings of both drivers and manifestations as they are reinforced in the manifestation domain and overall stigmatisation process (Stangl et al., 2019).

3.2.5. Outcomes

Finally, such stigmatising manifestations can result in various outcomes (Stangl et al., 2019). This may include being accepted or unaccepted by healthcare services, the availability of resources such as that of VEEG equipment that is needed for PNES diagnostic purposes (Brown et al., 2011), as well as adherence to treatment and advocacy. Stigmatising manifestations may also influence the outcome of both patients' and HCPs' resilience in challenging current stigmatising beliefs held about PNES (Brown et al., 2011; Stangl et al., 2019).

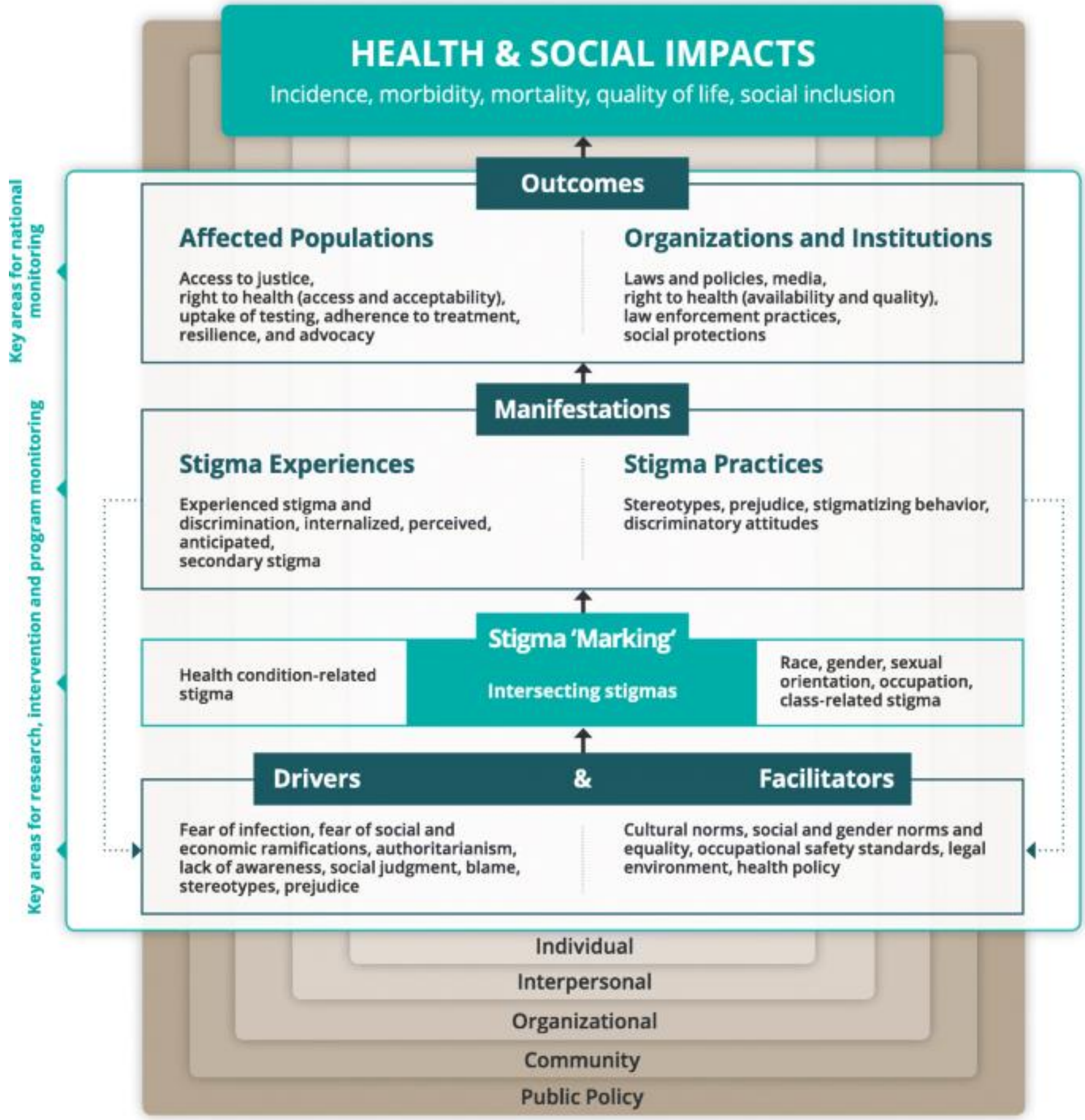

Figure 2: *The Health Stigma and Discrimination Framework formulated by Stangl et al. (2019).* Appendix B- Copyright (2019) permission.

3.3. Critique of the Theory

The Health Stigma and Discrimination Framework is a fairly new theoretical framework that has been developed (Stangl et al., 2019). Owing to the recent nature of this framework, more research is required to determine its effectiveness and to offer a thorough critique. However, in general, stigma theories have been critiqued.

One form of criticism is that stigma cannot be operationalised in order to offer a holistic definition (Fox et al., 2018). Stigma tends to be defined according to what a person is being stigmatised for, such as factors relating to class, physicality, or having a mental illness; however, the experience of stigma is too broad to pin down according to specific categories (Fox et al., 2018). To counter this, Stangl et al. (2019) argue that their framework is able to demonstrate the fluidity and complexity of the interconnections that exist among various individuals' experiences, by exploring the broader social, economic, political, and cultural factors that structure stigma.

Generally, in terms of health-related stigma theories, there tends to be a lack of relationship between the psychological and sociological factors that contribute to stigma (Clair, 2018). It is more advantageous when these two factors are examined together so as to determine the production of health disparities; for example, one could focus on the mechanism of family stress and pressure as a psychological factor, but then also take into consideration the sociological factor of the unequal distribution of health resources which leads to stigma (Clair, 2018). Within The Health Stigma and Discrimination Framework, focus is given to stigmatising experiences which are related to psychological factors, as well as facilitators involving occupational safety standards and health policy which are based on sociological factors (Stangl et al., 2019). Thus, this demonstrating the framework's beneficial use, due to drawing upon both psychological and sociological insights.

Additionally, stigma tends to be perceived as only being directed towards those who are vulnerable (Stangl et al., 2019). The framework thus seeks to explore whether those in power, inclusive of HCPs, may also experience stigma. By doing so, the authors hope to underscore that all people can perpetuate, internalise, perceive, experience or anticipate health-related stigma (Stangl et al., 2019). This new framework thus serves as an insightful approach towards understanding how stigma manifests.

3.4. Chapter Summary

Within this chapter, I provided an explanation of the theoretical framework that will be used to analyse and understand the current findings obtained for my study. The Health

Stigma and Discrimination Framework formulated by Stangl et al. (2019) is viewed as the most appropriate for this study due to it specifically focusing on how stigma unfolds within a health-related context. Particular attention is paid to mental health, as well as the factors that play a role in heightening stigma such as one's social class standing; thus, resulting it in being socio-politically applicable to South African research. More research is required to identify the limitations of this specific theoretical framework. In the next chapter, I describe the research methodology used for this current study.

Chapter 4: Methodology

4.1. Introduction

In this chapter, I present a thorough discussion in relation to the research methodology which guided the current study. I reflect back on the research question, as well as the research aims and objectives that were outlined in the beginning of this thesis in Chapter 1. I then describe the research design, sample characteristics, and data collection procedures. Thereafter, is an explanation of the data analysis procedure. Finally, the chapter ends with a provision of the trustworthiness processes and ethical considerations for this study.

4.2. Research Question

The research question addressed in this proposed study is as follows:

- What are HCPs' stigma towards people with PNES?

4.3. Research Aims

With attention given to HCPs' stigma towards people with PNES, the following study aimed to focus particularly on:

- Understanding HCPs' experience and knowledge of PNES;
- Discovering the attitudes held by HCPs towards working with PNES as a mental health condition, and
- Exploring HCPs' views of how their stigma manifests towards people with PNES.

4.4. Research Design

An explorative qualitative design was implemented for this study. This type of design primarily focuses on addressing new areas of qualitative research and phenomena that are yet to be discovered (Suter, 2012). Thus, it is useful to this study as the topic of HCPs' stigma towards people with PNES has not been thoroughly explored in South Africa. An explorative qualitative design is also open-ended in nature, which in turn helped to capture a detailed description of HCPs' opinions on PNES (Silverman, 2016). Rather than finding a solution to an existing problem, such a design looks at a topic of interest and derives meaning and understanding from it (Suter, 2012). Within this study, the particular use of semi-structured individual interviews aided this design, and I, as the primary investigator, was able to gather rich linguistic data owing to the vast number of answers that could be obtained. This, in turn, produced an insightful analysis and assisted with the development of themes.

4.5. Sampling and Participants

Both the purposive and snowball sampling methods were implemented to recruit participants. Purposive sampling refers to the use of specific selection criteria to recruit participants that are the most representative of the population (Wagner et al., 2012). Snowball sampling includes an initial phase where a small amount of individuals are initially approached and asked to participate (Wagner et al., 2012). These individuals are then asked to identify other individuals for means of participation, who, in turn, identify others. This process continues until data saturation occurs (Wagner et al., 2012). Data saturation is a process whereby the researcher is able to determine a point of redundancy in the data gathered (Faulkner & Trotter, 2017).

Before I could start recruiting participants, I first obtained permission to conduct my study from Stellenbosch University's Health Research Ethics Committee (HREC) (ethics reference number: S21/03/033; Appendix C). Thereafter, I had to obtain institutional permission to recruit participants from the Unit for Epilepsy at a private hospital in the Western Cape, and from the Department of Neurology at a public hospital in the Western Cape (Appendices D and E; please also refer to section 4.9. on ethical considerations for more detail). The reasoning for approaching specialists in PNES at these two hospitals initially was because they have access to VEEG monitoring and are able to provide an accurate diagnosis of PNES.

Upon receiving the relevant institutional permissions from the two hospitals (Appendices D and E), my supervisor began reaching out to HCPs that worked in these hospitals; she specifically contacted those HCPs who had specialised in PNES diagnostic, treatment and management procedures. She informed them through email about the purpose of the study and that I, as her student, was looking to recruit participants. After they notified my supervisor of their interest in participating and provided their permission for me to contact them, she gave them my contact details and notified them that I would soon be contacting them via email to confirm their participation and offer more details about my study (please refer to Appendix F for the email invitation). After the commencement of their interview, these specific HCPs were asked if they were aware of any potential HCPs that may be interested in participating, and if they could provide my supervisor and I with their contact details. These potential participants were then contacted via email and arrangements were made for an interview. This in turn led to the formation of the final sample, consisting of different HCPs that worked in either private practices/hospitals, or public hospitals, both within and outside the Western Cape.

Information pertaining to the inclusion criteria for this study was confirmed by the use of a biographical information sheet (Appendix G). In order to participate in this study, HCPs had to have had at least one year of experience with the diagnosis and/or treatment and management of individuals with PNES. Such HCPs would also need to have had recent interactions with individuals with PNES. All interviews were conducted in English, as the HCPs were highly trained and qualified professionals, who were fully conversant in English and comfortable with using this language as the medium for interviews. Therefore, my study and sample were not limited due to language constraints.

Data saturation was reached after conducting the 13th interview, upon which no further interviewing was done. Thus, the final sample consisted of 13 HCPs; in particular, one general practitioner, two psychiatrists, four psychologists, and six neurologists. Whilst I did try to include nurses and their perspectives within my study, they unfortunately did not form part of the final sample. This was mainly owing to their busy work schedule and limited time, as well as lack of communication or response to emails in general.

4.6. Data Collection Procedures

As stated in the above section, 4.5., all HCPs that were identified either through my supervisor or through snowball sampling from other HCPs, were sent an email invitation. The email invitation (Appendix F) served as an introduction about myself, and provided HCPs with the aims and objectives of this study. It also included matters related to how data would be collected, that being the biographical information sheet and semi-structured individual interview, and the time needed to complete such procedures. The invitation also assured HCPs that their identity would be protected and that all information that they provided would remain confidential. They were also informed that participation was completely voluntary, and that they could withdraw from the study at any time they wished to do so. Whilst some HCPs agreed to participate directly after receiving the email invitation, others preferred to first speak to me telephonically before agreeing to participate. After agreement was reached, each HCP and I arranged a specific meeting date and time for the interview. The HCPs were informed that I could conduct the interview either in-person, or on an online platform such as Zoom or Microsoft Teams, according to their suitability. Prior to the interview and after agreeing to participate, the HCPs were also sent an informed consent form to confirm their participation (Appendix H), plus a biographical information sheet (Appendix G) for means of collecting demographic information and ensuring that they met the inclusion criteria. Such documentation had to be completed before the commencement of the interview.

Seven of the interviews were conducted over Zoom, and six were conducted over Microsoft Teams. In particular, two out of the seven Zoom interviews were also conducted telephonically, owing to the HCPs having technical difficulties with Zoom upon the commencement of their interview. The interviews ranged from a minimum of 27 minutes to a maximum of 50 minutes. As stated in the previous section, 4.5., all interviews were conducted in English. All 13 HCPs were also able to communicate in English and did not mention any discomfort in the use of this language. At the beginning of the interview, each HCP was greeted in a friendly manner and were asked if they were comfortable and ready to start the interview. They were also asked verbally for their permission to have the interview audio-recorded.

I used an interview schedule (Appendix I) to guide the flow of conversation within the semi-structured individual interviews. Questions on the interview schedule were formulated with the help of my supervisor, plus a review of current literature, and were specifically linked to the aims and objectives of this study. The questions were broad and open-ended in nature, based on the HCPs' experience and knowledge of PNES, and the stigma related to the condition. HCPs' work and relationships with their PNES patients, their understanding of PNES as a condition, attitudes relating to diagnostic and treatment procedures, and viewpoints on their stigma directed towards PNES patients, were explored.

At the end of the interview process, I asked each HCP if they could potentially provide my supervisor and I with the contact details of other HCPs that may be interested in participating in this study. I then thanked each HCP for their time and effort. Some HCPs reiterated that they would like to see the findings of the research; I confirmed that they would be able to access the final report.

4.7. Data Analysis

Audio-recordings of the interviews with each HCP were transferred to my personal laptop, which was password-protected, and backed up on the cloud/drive, which was encrypted for safety and security purposes. I then transcribed each interview by listening to the audio-recordings, and checked each transcript to ensure that there were no errors and that it matched the recording. I transcribed and performed data analysis procedures concurrently with the interviews, for the purpose of establishing the point at which data saturation was attained. Data saturation is a process through which, after analysing the data, no new information is identified and a point of redundancy is reached. It provides the means for understanding that owing to new information being obtained, data collection can come to an end, and no further data is required for analysis (Faulkner & Trotter, 2017).

The Health Stigma and Discrimination Framework proposed by Stangl et al. (2019) was used in a hybrid deductive and inductive manner to analyse the semi-structured individual interviews; this will be discussed in the next chapter. Furthermore, the semi-structured individual interviews were also analysed through the reflexive thematic principles proposed by Braun and Clarke (2019). Reflexive thematic analysis refers to a qualitative method that is used to analyse qualitative data. Individuals' experiences and perceptions are explored thoroughly through this method and patterns of meaning are identified within a dataset (Braun & Clarke, 2019). In this case, it was the HCPs' experiences and perceptions of their stigma towards people with PNES that were explored. The process of a reflexive thematic analysis occurs through six phases (Braun & Clarke, 2019).

Phase one entailed becoming familiar with the data (Braun & Clarke, 2019). Within this phase, I listened to the audio-recordings repeatedly. I printed my transcripts and reviewed and re-read them for the purpose of establishing accuracy. Whilst listening to and reviewing the content of the data, I made note of any information that stood out and intrigued my thought process, but that also showed a pattern. I specifically highlighted particular phrases, and also made comments in the margins of each transcript next to the answers that the HCPs had given.

Phase two is where codes were initially generated (Braun & Clarke, 2019). I specifically began with the formulation of codes by looking for a feature of data that was possibly useful to the research topic and question at hand. I also identified concepts linked to the literature review and theoretical framework that could also be used as codes. I did this by again highlighting information, but this time I used different coloured highlighters to match the research topic, information from the literature review, and the theoretical framework. This helped me to easily identify which pieces of information provided by the HCPs fitted in with what I was looking for and to assist with generating codes. I then made further notes in the transcripts by writing certain words that correlated with the research topic next to the highlighted pieces of information or the HCPs' answers, which in turn served as codes. Upon reviewing each transcript, I formulated new codes and also revised existing ones.

Phase three was based on searching for themes (Braun & Clarke, 2019). A theme demonstrates meanings obtained or patterned responses which are identified in the dataset based on the construction of codes (Braun & Clarke, 2019). I actively examined the data to identify similarity or overlap between codes. Every so often, particular extracts within the transcripts were associated with more than one code. Therefore, this resulted in multiple themes being linked to specific extracts, as well as overlapping ideas which appeared throughout the transcripts. In order to organise the data, I created a table to list all the HCPs' answers in relation to the codes formulated and to track how many of the HCPs had given a similar answer, or information that matched a particular code. This in turn allowed me to group codes together, and categorise and relate them to broader themes. With the help of my supervisor, I then narrowed these broader themes into particular major themes associated with stigma, which is the focus of this study, as well as subthemes, whereby I could assign the codes generated. These themes served as potential themes which were reviewed in the next phase for means of relevance.

Phase four was a means of quality checking, which included reviewing potential themes (Braun & Clarke, 2019). In this phase, I reviewed themes with my supervisor to determine if they corresponded with the coded data and extracts from the transcripts. I also looked at whether there was enough information provided from the HCPs for each theme to sustain itself in a thematic map. I closely identified frequently occurring codes and themes within the dataset, and made note of any information that varied. This process then allowed me to eliminate the themes which were not prevalent or relevant.

Thereafter, in phase five, with the help of my supervisor, I appropriately named and defined each theme (Braun & Clarke, 2019). Phase six was based on the writing-up of the report. Within this phase, themes had to be presented logically to the reader, and demonstrate a flow in the story of data obtained (Braun & Clarke, 2019). This final phase is represented throughout the last two chapters of this thesis in which the findings are presented and related to specific literature, as well as explained through the theoretical framework deemed appropriate for this study.

4.8. Trustworthiness

Trustworthiness refers to the established rigour of a qualitative study (Connelly, 2016). Four proposed main criteria of trustworthiness were adhered to within this specific study; that being, credibility, transferability, dependability, and confirmability (Connelly, 2016). The method of reflexivity was also employed to enhance the quality of this study; it will also be discussed further.

4.8.1. Credibility

Credibility refers to ensuring that the research process is conducted according to principles of good practice and that research findings are submitted to participants in the study to obtain confirmation that the researcher has correctly understood their perspectives. This is also referred to as respondent validation or member checking (Bryman, 2016). In order to achieve credibility, I obtained an in-depth understanding of PNES, HCPs and stigma through thoroughly reviewing literature based on this topic. My research proposal was also examined by Stellenbosch University's HREC (ethics reference number: S21/03/033). I conducted member-checks within the interview process, by following up on particular answers which the HCPs provided, to ensure that I understood them correctly. Participants were made aware that participation was voluntary and that they would be allowed to withdraw from this study at any time. I also engaged in regular debriefing sessions with my supervisor; this allowed for a means of reflection in order to become aware of my potential biases, and to obtain new ideas regarding the findings of the research.

4.8.2. Transferability

Transferability is the extent to which results formulated can be transferred to different contexts or settings with other respondents (Korstjens & Moser, 2018). Within this thesis, a thick description based on the findings is provided. Readers will thus be able to draw their own conclusions based on the transferability of results.

4.8.3. Dependability

Dependability is where data remains stable over time under different conditions and allows for replication (Elo et al., 2014). In order to achieve this, a detailed description of criteria that were adhered to, as well as the research methodology, is provided within this thesis.

4.8.4. Confirmability

Confirmability involves ensuring that the researcher's findings are in line with the data (Nowell et al., 2017). Whilst conducting my research, I remained transparent, and constantly reassessed my assumptions through regular supervision sessions with my supervisor. All findings obtained were also reviewed by my supervisor to ensure that the data was sound and that potential limitations were reported.

4.8.5. Reflexivity

Reflexivity refers to a method through which researchers engage in a continuous form of self-awareness. It entails understanding how the researcher can have an influence on the research, and vice versa (Palaganas et al., 2017). It is thus important for me to provide my current position within this research.

I have always had a passion for neuropsychology and wanted to know more about the functions of the human brain from an academic viewpoint. At the time of conducting my research as a master's student, I was also an intern counsellor. PNES was a condition that I had explored for the first time. I am not aware of any individuals within my personal life that have either been diagnosed with this condition or who have worked as HCPs that specialise in PNES care. I therefore did not do this research for purposes related to such matters.

Within the stage of obtaining permissions to conduct my research, I found myself becoming slightly frustrated owing to the delay in the process of gaining approval. I applied for ethical clearance from the HREC in February 2021, and only obtained final ethical approval in June 2021. Thereafter, I had to obtain permission from both a private and public hospital in the Western Cape to recruit participants. Whilst the private hospital was quick to respond, their ethical approval process required my supervisor and I to complete various documentation and to communicate with the relevant authorities, which was at times difficult. In relation to the public hospital, I initially did not receive any response from them, despite my continuous efforts of trying to make contact with the relevant parties involved. This resulted in my supervisor having to make contact with respective individuals she had known at the public hospital, so as to help with my research approval. The public hospital also required me to submit my research proposal to the Western Cape Government's National Health Research Database (NHRD). Even after I received ethical permission from the NHRD, the hospital did not timeously inform me that I could start recruiting participants. Having waited for so long, it had become somewhat disheartening in terms of not knowing when exactly I would be able to proceed with my research.

When I started recruiting participants, I also did not receive a response from some of the HCPs I had emailed. This was initially difficult for me to accept, but as time progressed and after speaking about it with my supervisor, I became more understanding and started to realise that this was the norm, often owing to the HCPs' time-consuming work schedule. I was also not able to recruit any nurses owing to either their lack of response or extreme workload. This was a bit saddening as I truly would have appreciated their input.

Being a woman, and of a young age, I found it at times intimidating to conduct interviews with prestigious HCPs. However, owing to me having sufficient counselling skills as an intern counsellor, I found myself being able to understand my own projections, work well with participants from different backgrounds, and make note of my personal biases by engaging in a reflection process. With that being said, I did have difficulty in accepting some of the HCPs who displayed a defensive nature in relation to stigma; this was because I am someone who advocates for diminishing the effects of stigma related to mental health. However, speaking to my supervisor about this, helped me to process these matters. I also constructed a reflexive diary, where I reflected on my experience of each interview (Appendix J). This helped me to make sense of my experiences and thoughts.

4.9. Ethical Considerations

Prior to the commencement of this study, ethical approval was applied for from the Stellenbosch University's HREC. The HREC requested modifications to my initial proposal. Once these modifications were made, ethical approval was obtained on the 23rd June 2021, and the ethics reference number, S21/03/033, was allocated to my study (Appendix C). I also had to obtain institutional permission from both a private and public hospital in the Western Cape. The private hospital's ethical process required me to submit my research proposal for review with the Mediclinic Research Review Committee. The committee had also required my supervisor and I to complete a confidentiality and data processing agreement, and to obtain permission from the hospital's general manager. Ethical approval was obtained from the hospital on the 25th August 2021 (Appendix D). In order to obtain permission from the public hospital, I had to complete an online application with the Western Cape Government's NHRD. I also had to obtain written permission from the Head of Neurology at the public hospital. Final ethical approval from the public hospital was granted on the 14th October 2021 (Appendix E).

Further ethical procedures based on how the research was conducted are outlined as seen below. As previously stated in the above sections 4.5. and 4.6., my supervisor initially communicated with participants to obtain their permission for me to contact them. After obtaining their permission, I sent an email invitation to each participant (refer to Appendix F for the email invitation). They were provided with information about the purpose of this study, requirements of their participation, as well as how their participation could result in beneficial effects for their field of work. They were also advised that participation is completely voluntary, and that no remuneration would be provided for their participation. The HCPs did not incur any costs through their participation in this study, such as needing to travel, as the interviews were conducted according to a time and place that was suitable for them; this was also inclusive of online platforms such as Microsoft Teams or Zoom. Within the email invitation, participants were informed that if they were in need of internet data to conduct the interview online, such provisions would be made upon their request. After each HCP agreed to participate, I confirmed with them whether they had a stable internet connection, were in need of internet data, and which online platform they preferred.

Prior to the interview, I requested informed consent from each participant (Appendix H). Permission for the interview to be audio-recorded was also requested at the start of each interview. Participants were made aware that they were allowed to withdraw throughout the duration of this study, and that this would not pose any disadvantage to them, either personally or professionally. All interviews conducted online required a unique meeting passcode or link to access the interview, thus ensuring that only those who obtained such information would be able to enter the online meeting. I also conducted all the interviews, on my end, in a locked private room, to ensure that no-one else could potentially listen to the conversations and gather any information.

In order to protect the participants and ensure that confidentiality and anonymity is maintained, I have used pseudonyms for each participant, and the participants' qualifications and locations of practice are not reported in this thesis. This is of essence as it is likely that the HCPs may have been less willing to participate if they had presupposed that findings obtained from this study would demonstrate a negative reflection of them. HCPs were also only asked for their views in general regarding their attitudes, knowledge, and experience with PNES and stigma. Thus, no information pertaining to specific individuals being treated for PNES was required. This in turn allowed for the HCPs to protect the confidentiality of their patients.

All data that was collected and formulated throughout this study is stored in a secure place, such as in my supervisor's office cabinet, which is always locked. Any electronic files that were used in the duration of this study are password-protected and encrypted on my own personal laptop; they are also backed up on the cloud/drive which was also encrypted for safety purposes. My supervisor and I are the only individuals who have access to the files and the research report. We aim to publish the anonymised data of this completed study in a peer-reviewed journal. The original data will be stored for a period of five years, and will then be appropriately discarded.

This study was classified as medium-risk, as the research topic was based on stigma, which is sensitive in nature. There was a possibility that HCPs may experience discomfort when reflecting on their opinions of how their PNES patients experience stigma from them. All HCPs were informed that if they experienced any emotional distress, they would be referred to a healthcare professional at Welgevallen Community Psychology Clinic where they would receive the appropriate services, either in-person or online, at no cost to them. Please refer to Appendix K containing the letter of permission for receiving counselling services from the clinic. It must be noted that I paid detailed attention to the comfortability of participants within the interview process to ensure that they were at ease, to check if they needed a break, or to enquire if they did not want to continue with the interview. The HCPs did not experience any harm to the point where they needed counselling.

4.10. Chapter Summary

Within this chapter, I offered a detailed discussion on the research methodology for this study, which is inclusive of the research question, aims and objectives, and research design. Further explanations about the sampling and participant characteristics, as well as data collection and data analysis procedures, were provided. Thereafter, a description of the processes for maintaining trustworthiness and an account of the ethical considerations for this study, were outlined. In the next chapter, I will present the findings of this research.

Chapter 5: Findings

5.1. Introduction

In this chapter, I present the key findings of this study. I will first report on the demographical characteristics of the participants. Thereafter, I will discuss the six main themes which I identified during data analysis, namely: (i) contextual factors; (ii) HCPs' frustration with PNES patients; (iii) HCPs' relative level of knowledge; (iv) diagnostic terms; (v) stigma, and (vi) strategies to reduce stigma. Furthermore, these themes, together with the subthemes, will be reported within this chapter in relation to The Health Stigma and Discrimination Framework (Stangl et al., 2019).

5.2. Demographic Characteristics of Participants

This study's sample consists of 13 participants in total. The participants are HCPs who specialise either in the diagnosis, and/or treatment and management of PNES. Of the 13 HCPs, one is a general practitioner, two are psychiatrists, five are clinical psychologists, and six are neurologists. Their age ranges from 26 to 63-years-old, with a mean age of 49. There are six female HCPs, and seven male HCPs. Their number of years working as a HCP range from two to 34 years, with a mean of 22 years. The table below provides a summary of the demographical information obtained from the participants' biographical information sheets.

Table 1: *Demographical Characteristics of Participants*

Participant	Age	Gender	Specialisation	Years working as a HCP
P1	44	Male	Clinical Psychologist	12
P2	63	Female	Clinical Psychologist	32
P3	55	Male	Psychiatrist	30
P4	35	Female	Neurologist	11
P5	59	Male	Clinical Psychologist	30
P6	55	Female	Clinical Psychologist	23
P7	44	Female	Psychiatrist	22
P8	60	Male	Neurologist	30
P9	26	Female	General Practitioner	2
P10	43	Female	Neurologist	11
P11	41	Male	Neurologist	18
P12	49	Male	Neurologist	25
P13	58	Male	Neurologist	34

Note. Participant code: P = Participant; 1= number assigned to the participant based on the order in which the interviews was conducted.

5.3. Application of Theoretical Framework

This study focuses on the stigma directed towards PNES patients by HCPs. Whilst using a reflexive thematic analysis approach (Braun & Clarke, 2019) to analyse the data, I paid particular attention to the information in line with the aims of this study, which spoke to the HCPs' experiences of working with PNES and their knowledge of the condition, the attitudes that they held, and their views based on how stigma manifests. I also was mindful of matters that are important to the South African context, such as a potential lack of resources within the healthcare system that could possibly contribute to both health and class-related stigma. Through the use of The Health Stigma and Discrimination Framework (Stangl et al., 2019), I was able to conceptualise my study and become familiar with understanding the data obtained. The theoretical framework allowed me to identify negative drivers and facilitators which heighten health stigma, and positive facilitators which lessen the effect of stigma. Additionally, I was able to see how stigma intersects due to patients experiencing stigma as a result of having PNES, but also because of their economic deprivations, and gender. Stigmatising experiences and practices related to discriminatory attitudes, prejudice and harmful behaviours from HCPs in general, were noted. In turn, the outcomes of stigma, as evident in the report by the HCPs, were those which prevent PNES patients' access to rightful healthcare. By taking into consideration all of these factors, six main themes were identified with various subthemes; they are summarised in the table below:

Table 2: *Summary of Themes and Subthemes*

Main Theme	Subtheme
5.4. Theme 1: Contextual Factors	5.4.1. Lack of Accessibility 5.4.2. Lack of Continuous Care 5.4.3. Lack of Staffing 5.4.4. Lack of Time 5.4.5. Lack of Resources 5.4.6. Lack of Collaboration with Psychiatry and Psychology
5.5. Theme 2: HCPs' Frustration with PNES Patients	5.5.1. PNES Patients' Inability to Accept their Diagnosis 5.5.2. HCPs' Difficulties with their Patients' Personality
5.6. Theme 3: HCPs' Relative Level of Knowledge	5.6.1. The Diagnosis of PNES 5.6.2. Difficulty Distinguishing between PNES and Epilepsy 5.6.3. HCPs' Relative Level of Education and Training 5.6.4. HCPs' Relative Level of Knowledge in Practice
5.7. Theme 4: Diagnostic Terms	5.7.1. Inappropriate Diagnostic Terms 5.7.2. Multiple Diagnostic Terms
5.8. Theme 5: Stigma	5.8.1. HCPs' Personal Stigma towards PNES Patients 5.8.2. HCPs' Lack of Accountability 5.8.3. Stigma within a Hospital Setting 5.8.4. HCPs' Dismissiveness and Negative Attitudes 5.8.5. Referral 5.8.6. The Realness of Symptoms
5.9. Theme 6: Strategies to Reduce Stigma	5.9.1. Education and Enhancing Knowledge within the Field 5.9.2. Equality 5.9.3. Awareness of Diagnostic Terms 5.9.4. HCPs' Genuineness and Empathy towards PNES Patients

5.4. Theme 1: Contextual Factors

This theme is based on external factors that many of the HCPs had spoken about, which were viewed as indirectly influencing stigma. They are related to the major problems that exist within the South African context. These are inclusive of a lack of accessibility to healthcare services and continuous care for patients, a lack of staffing and HCPs not having enough time to see their patients, and a lack of resources in general. A few HCPs also mentioned that within their hospital setting, there is a lack of collaboration with the disciplines/departments of psychiatry and psychology.

All of these contextual factors are related to The Health Stigma and Discrimination Framework whereby they are defined as negative facilitators; these are based on a lack of equality, occupational safety standards, laws, and health policies that contribute towards or increase stigma (Stangl et al., 2019). In some situations, these contextual factors are also recognised in the theoretical framework as intersecting stigmas having to do with health and social class, resulting in patients experiencing a form of discrimination and delay in treatment (Stangl et al., 2019).

5.4.1. Lack of Accessibility

This subtheme is based on the HCPs and their services not being readily available for patients (seven out of the 13 HCPs spoke about such matters). The hospital that some HCPs worked at were described as being central and difficult for patients to directly travel to. It was also noted that there is an apparent disparity among the expertise of HCPs and equipment available, according to the location and/or level of the hospital. HCPs stated that they often have a bottleneck of patients in waiting. According to the HCPs, their lack of accessibility results in patients feeling that they are not a priority and that their concerns do not matter within a healthcare setting, thus resulting in stigma. The following quotes illustrate the HCPs' lack of accessibility in relation to the information discussed above:

> *"So, it's very centralised, and you have someone from Khayelitsha with Psychogenic Non-Epileptic Seizures, and it can be seven years before they are diagnosed. And then they might manage to get to hospital and then they need psychological interventions and neurology interventions and it's expensive, and it's far and unreasonable."* (P7)

> *"…on a kind of more healthcare, wider healthcare um perspective, it's quite um it's quite clear that…the only neurology services available in the state sector are in tertiary hospitals. So, where there should be neurology services available in secondary hospitals, they're all in tertiary hospitals, which forms a bottleneck…a*

> *long waiting list for monitoring, it can be a problem sometimes, because because of the bottleneck effect that there aren't any people monitoring, any monitor anywhere else than in the state other than here [reference to hospital] in the Western Cape. Not sure, I don't even know if there's monitoring facilities in, in um, so in Free State and so forth."* (P12)

5.4.2. Lack of Continuous Care

This subtheme is based on PNES patients not receiving a form of continuous care and support from their HCPs, which in turn results in them developing a negative perception of their treating physician. It is also related to the HCPs not being able to follow-up with their patients. Five HCPs described that there was a lack of continuous care for patients:

> *"…the lack of continuity for those patients seeing different people at every visit, I think is, is probably a bit detrimental…I think once the diagnosis has been made, um I would strongly favour them um seeing the same person repeatedly and for that the government hospitals are probably not ideal with registrars moving on and rotating."* (P10)

> *"The more the individual doesn't have support systems, you know, at precisely at the time when they most needed, which is understanding and compassion, and all of those things…[their] perception of the doctor [is then that he/she] thinks there's nothing wrong with you."* (P13)

Additionally, some HCPs also explained that in certain instances, sending their patients home and following up on treatment became challenging. This was owing to their patients not receiving enough support from their family and friends, and often living in a stigmatising household:

> *"If patients um, also find that um you know, in terms of, of just uh motivating; if they don't have enough support uh at home, it's also very difficult for them then to access services because they sometimes need to depend on someone else to bring them to the hospital…family members might have negative attitudes towards the illness, uh and might also, you know, just bluntly, would get a bit fed up with the family member, that has these symptoms and uh you know, support can also be lacking in the family home."* (P3)

5.4.3. Lack of Staffing

This subtheme has to do with there being not enough staff members that specialise in the diagnosis and treatment of PNES. Seven HCPs stated that there was a lack of staff, especially psychologists, followed by a lack of neurologists and healthcare physicians in general. The lack of specialists could be related to PNES not being taking seriously as a diagnostic entity, resulting in HCPs wanting to work with other conditions. The quotes below are based on the HCPs' description of limited staff members:

> *"So here we've got a severe shortage of psychologists, and I I think clinical psychologists um, [they are] the most important part of managing um these patients…we've got very limited access because of the number that is employed."* (P12)

> *"… one of the biggest things is staffing…although I've been here from 2002; from 2002 till about I think six or seven, I worked alone for like four or five years or so, and before I had staff and then oh, they, they they more or less remained here, but they left and came and that. So, we had a very stable service um up until I would say 2016. Um and then from 2017, I've been working alone again."* (P6)

> *"…I've struggled to find other people to, you know, um to do just that. People generally want to do general neurology…it's a chronic condition with with um lots of um comorbidity in the sense you have to take on families, you have to take on people who are anxious, people who at short notice are, want help when they have seizures, or when they get side effects on medications or um their troubles at work…you need the right person who wants to take that sort of thing on…that is a barrier, no question."* (P13)

Some HCPs described that they did not have a multidisciplinary team to rely on, and could not sit in on different HCPs' practices in order to enhance their knowledge, which they found extremely challenging. Owing to them not being able to obtain different viewpoints, they found themselves being less able to guard against stigmatising beliefs that exist within the hospital culture:

> *"…just getting the multidisciplinary approach, um and getting the team together, you know. Overseas, they have uh clinics, multidisciplinary clinics, um you know, set up to manage these patients, which we, I think you know, that would be a lovely thing to, to*

> *um start in the future. So, so that's a challenge we should try and overcome. The other thing is that um the, the big thing is stigma…I think attitudes and and the way people, clinicians think about these patients, is also a challenge that we, we have to overcome."* (P4)

5.4.4. Lack of Time

This subtheme is based on the HCPs feeling overwhelmed with a lack of time. They described their workload as being time-consuming, and stated that they were unable to dedicate enough of their time to see their patients and perform assessment or treatment procedures. Again, they believed that their patients may interpret them as being stigmatising owing to not being able to put in the effort to see them. Of the 13 HCPs, 10 of them communicated these concerns as highlighted in the following quotes:

> *"So once we've made the diagnosis, [we] discuss with the patient they need ongoing support. Uh and, and our team here, they are excellent, but they are overwhelmed. No other word for it. So, so there's significant human resource limitations."* (P11)

> *"We often only report on the EEG after the patient has been discharged. So, let's say we monitor from Monday to to Friday, there's a, a few events um recorded. Um it's not possible from our other workload perspective to do the review of the EEG during the period that the patient is here."* (P12)

> *"…so I think maybe to build a a real relationship, but I think [that] takes a bit of time and that's especially in a state hospital…so the patients are coming to me after having seen the registrar. I don't have an allotted time with them. So, I think it's, it's usually very difficult to sit down with someone and just ask within the first two minutes, what's bothering you, what's causing this? And I think that doesn't build confidence for a relationship."* (P10)

5.4.5. Lack of Resources

Many of the HCPs (10 out of 13) stated that within their work setting there was a lack of resources in general. They described not having enough equipment, as well as assessment and treatment options. They found that most of their patients were not able to afford the treatment provided and did not have access to medical aid. The public sector was described as being the most resource depleted in comparison to the private sector. The type of stigma seen here is a form of intersecting stigma related to a patient's social class and inequality according to the number of resources available. The following quotes shed light on the lack of resources available:

> *"Well, we have all the resource constraints of a public health system. Large numbers of patients, large numbers of patients um from different socio-economic circumstances and backgrounds...We have enormous caseloads across the board. So, you know resources are uh is always a challenge. And um mental health problems are mental health problems, that they take as long as they take…you know, mental health problems are not going to conform to how little resources are available."* (P5)
>
> *"I think the one barrier is a, is a resource constraint in terms of um most uh hospitals don't have video-EEG monitoring…so I think there's maybe three state hospitals in the country that have video-EEG monitoring, maybe four; I stand to be corrected. And there are hundreds uh uh thousands and thousands of patients with the condition."* (P11)
>
> *"I think there's a vast difference uh on, both in treatment in in all of these factors, that is that is related to economic discrep discrepancies between uh patients. So, the treatment provided to someone who has a deep pocketed medical aid will likely be different to that of a patient who is at [a public] hospital, with very lit-little, if any access to psychology services. So likely, if I'm at a private hospital, I could see a psychologist once a week for a year."* (P8)

Although the majority of HCPs stated that there was a lack of resources in general, some of them (seven HCPs) indicated they were able to access essential resources such as EEG when necessary. Many of those who worked in the private sector or within tertiary level hospitals stated that they did have a sufficient amount of resources:

> *"I must uh, you know, be honest in that in my experience, we've been fortunate that uh I, I worked at a tertiary level hospital…where they are well equipped with long-term monitoring, EEG equipment, MRI brain, etcetera, and in the private sector as well."* (P4)
>
> *"Um so [the public state hospital] is relatively well, well equipped. Um we've got relatively, we've got more resources than, you know, your other local clinics in the Western Cape, and the Western Cape is far far beyond the other provinces."* (P9)

5.4.6. Lack of Collaboration with Psychiatry and Psychology

This subtheme is based on there being a lack of collaboration among different disciplines, departments, and HCPs that work with PNES. Five HCPs described that the discipline of psychology was not taken seriously within their medical setting. Some HCPs disclosed that there were even physical barriers that existed in the hospital between the Departments of Neurology and Psychiatry/Psychology. Problems with communication between these different departments were also noted. The following quotes demonstrate the lack of collaboration with Psychiatry and Psychology:

> *"…I think to uh um to an extent, maybe a larger extent, I think it's the field of psychology as well that's not um so entwined uh within the, the healthcare system. Um and that could be because of policy…policy in that um maybe the departments of health, are are not seeing it is as uh so essential…Psychology is not taken so seriously…we still have the stigma that if you see the psychologists then you uh, you off centre. Right, so there is that general stigma to psychology."* (P6)

> *"So, I think the very tenets of how we see psychological distress and how psychological distress is prioritised in society is problematic. Um and that translates into how medical training happens. Um and how that medical conditions are prioritised in emergency rooms, um in busy outpatients' departments, um how Western medicine sees patients, the eight-minute consults, all of that. It's just uh, it's [a] very deeply entrenched framework…one can reduce it to the word stigma."* (P7)

> *"There's poor communication sometimes. So, psychiatry services tend uh again largely I would assume for historical reasons to be cut off uh from the rest of the hospital's functioning quite, quite a bit…they'll often operate in a separate building which immediately puts them, uh you know, physical barriers are very important. Um so there's that enormous physical barrier. In this hospital, there's a quasi-physical barrier, for example, just more of the same is, psychiatry is exclusively in the, the bottom of this hospital. But I think it's a, it's a very common phenomenon…relates to incarcerating mentally ill patients in a different building."* (P8)

5.5. Theme 2: HCPs' Frustration with PNES Patients

This theme is based on the HCPs' difficulties and frustrations in relation to their work with PNES patients. The HCPs found that the majority of their patients struggled to accept their PNES diagnosis, which prevented positive progression. HCPs also stated that they had the most difficulty when working with patients who presented with personality issues.

In the theoretical framework (Stangl et al., 2019), the HCPs' frustration with their patients are related to drivers, and stigmatising practices based on the HCPs holding preconceived negative evaluations, and demonstrating discriminatory attitudes, possible stereotyping, and a form of social judgement towards their patients. Furthermore, by being frustrated with their patients it can affect their patients' access and acceptability within the healthcare system (Stangl et al., 2019).

5.5.1. PNES Patients' Inability to Accept their Diagnosis

This subtheme is based on the patients holding on to or finding it difficult to let go of their epilepsy identity, which in turn resulted in them not being ready to commit towards moving forward in their PNES diagnostic and treatment plan. The HCPs described having difficulties with their patients' willingness to explore the psychological and emotional components of their condition. They also found that many of their patients did not return to them for further care. As a result, the HCPs expressed that they experienced many complications in management of their patients' condition and forming a relationship with them. Seven HCPs spoke about their patients' inability to accept their PNES diagnosis as seen in the following quotes:

> *"I think a lot of them have uh, they strongly believe it that they have uh epilepsy…to some patients it becomes very baffling when they say that, you know, um it's like all these tests you've gone through um show that you you don't have uh epilepsy…and then they say, so what now?…and um you know I'm not sure how many of them are actually going for therapy um and and to what extent it's helping them. So, I don't know what the end of it is, you know, the the, whether treatment ever helped, whether they have attended, whether they have completed."* (P6).

> *"So it's related to difficulties in being able to know affect and know what the effects are, work with their affects, think about their affects, think about relational or psychosocial issues, uh in a mental kind of way. Uh so that's one reason that sometimes these patients can be difficult to work with…it's just a foreign way of thinking, and some, some of them might be quite concrete and hark back to fact but yes, I have this epileptic problem and so on…they more inclined to talk about physiological symptoms, physical symptoms, somatic symptoms than they are to talk*

> *about emotions or thoughts. So that, I would say, would be the most typical challenge."* (P5)

> *"…so I think it can make some doctors even a bit aggressive towards the patient…um and I think if there's poor insight from the patient side as well, um who don't agree with the diagnosis, the relationship can break down, and then the patients often end up um looking for another um healthcare provider."* (P10)

5.5.2. HCPs' Difficulties with their Patients' Personality

Some HCPs (five out of 13) disclosed that they felt frustrated working with certain PNES patients due to their patients' personality. Owing to having difficulties with working with these specific patients, they found that they also had problems with transference and countertransference whereby they projected their negative feelings or had strong emotional reactions towards their patients within a therapeutic setting. The following quotes illustrate the information above:

> *"…sometimes it's frustrating, you know, when the level of denial might be high, uh the level of correctness is very high, uh or the level of disavow because of course, I suppose, ya, I suppose the the really complicated ones would be when it's um, when there are pronounced personality problems…personality problems would be over represented in a sample of somatic symptom disorder patients…and personality patients with personality problems are renowned for you know, by definition, they are difficult to work with because of the defences that they use."* (P5)

> *"But when there's comorbidity, that sort of borderline personality disorder is not all therapists want to work with that, or does find it difficult to work with a hysteric sort of personality. And so, in terms of that, I would say, again, it will be the therapist personal training and reference and their own comfort around working with specific patients. Sometimes people can be um picky in who they want to work with and that's also their prerogative. Um so not everyone um has the need to or want to work with patients with I assume this these symptoms as well…I think when there's character pathology that goes with it…there's more transference or countertransference, then, I guess, one can be um caught off guard, off balance, on attack."* (P1)

5.6. Theme 3: HCPs' Relative Level of Knowledge

This theme is based on the HCPs' description of their limited knowledge. Some of the HCPs stated that at times, they found it difficult to diagnose PNES, and also struggled to distinguish it from epilepsy. A few HCPs also stated that they had not received enough education on PNES. In general, it was indicated that, owing to the lack of academic courses on Functional Neurological Disorders, it prevented other HCPs from specialising in the diagnosis and treatment for PNES. Furthermore, the HCPs also commented on how their lack of knowledge was demonstrated in practice and that they could not assist their patients properly. Many of the HCPs believed that not having enough knowledge, was the main reason for stigmatisation towards patients.

In regards to The Health Stigma and Discrimination Framework (Stangl et al., 2019), it is noted that when HCPs have a lack of knowledge, they can be ineffective in their diagnostic and treatment processes. This is seen as a driver based on a lack of awareness, as well as a negative facilitator whereby there are limited occupational safety standards or health policies implemented to ensure adequate education or training for HCPs. As a result, it can lead to HCPs directing their stigma towards their patients' health condition, namely an intersecting stigma (Stangl et al., 2019). Patients are thus likely to endure the stigmatising experience that their HCPs do not have enough knowledge to understand and help them, which in turn makes them feel othered and as if they are not obtaining the rightful care (Stangl et al., 2019).

5.6.1. The Diagnosis of PNES

This subtheme refers to how and why HCPs found it difficult to diagnose PNES. A few HCPS (five out of 13), stated that they did not understand PNES, which resulted in a misdiagnosis. In general, they also found it challenging to make the diagnosis, owing to not knowing how to engage in appropriate communication with their patients. The quotes below show the HCPs' relative limited knowledge in relation to the diagnosis of PNES:

> *"…it can be a misunderstood um diagnosis, and or people don't have the deeper and more understanding or knowledge, theoretical knowledge behind it."* (P1)
>
> *"…I think uh misdiagnosis and, you know, um mis-investigating is is quite a big problem as well. So, so if I have to summarise my experience in terms of how I feel having seen these patients, I think number one, it's challenging. It's challenging to make the right diagnosis, one has to make um you know, take a stepwise approach in and approach the patient holistically…management of these patients is challenging,*

> *in that um, number one, it's it's giving them the diagnosis and how to do it in the correct manner, so as to not um you know, make the patient feel as though they, they don't have an illness and that we're disregarding their illness."* (P4)

The HCPs also described having a lack of diagnostic certainty owing to not being able to rely on EEG equipment at times, and having to use their own expertise:

> *"…but the problem, of course, is that some forms of epilepsy, you may not see seizure activity on an EEG, depending on where the focus is…the EEG is not, doesn't show anything, then we would not have a great amount of certainty."* (P12)

5.6.2. Difficulty Distinguishing between PNES and Epilepsy

This subtheme is based on how the HCPs (seven out of 13) found it difficult to distinguish or understand the differences between PNES and epilepsy. They stated that they had challenges in understanding what causes PNES, and found it especially complexing to understand and work with PNES patients who had comorbid epilepsy. The following quotes demonstrate the HCPs' difficulty in distinguishing between PNES and epilepsy:

> *"So, for me, it was, it was quite um you know, difficult to kind of label this, you know, non-functional, because in the back of my mind, I was still thinking, you know, what, what, isn't there something underlying that I'm missing?…the patient just had a seizure and I was trying to differentiate what was the cause of this seizure…I actually do not know exactly what the cause is…it's just not the type of epilepsy that we are used to seeing."* (P9)

> *"Um, well you know there's, there's a significant um comorbidity or it coexists. So about 30% of people with non-epileptic seizures have epilepsy…epilepsy is also quite complex…so in many ways they similar and epilepsy itself can be triggered by um, seizures can be triggered by uh stress…epilepsy itself can be very difficult to diagnose and psychogenic non-epileptic seizures can look a lot like epilepsy. So, I think we're very careful to be confident of one over the other."* (P7)

> *"So, it's very difficult to distinguish in clinical practice between the two. And we also know that what further complicates the matter is that epileptic and non-epileptic seizures can occur simultaneously in the same person. So, it's not either or, so if you have non-epileptic seizures, one should be careful not to exclude uh possible true epileptic seizures, uh it can sometimes be overlooked."* (P3)

5.6.3. HCPs' Relative Level of Education and Training

Some HCPs stated that they did not receive formal education or training on PNES (five out of 13 HCPs). They also stated that PNES courses did not receive enough attention within an academic environment, in general. Due to the lack of exposure to PNES, the HCPs reported that many of their other colleagues did not make the effort to further educate themselves and specialise in PNES care. The quotes below demonstrate such information:

> *"…some people maybe have not been approached with with such a patient and therefore they, you know, they're not gonna talk about it or read up on it. It's definitely not something that was, was, well in my undergraduate training was really covered…I mean, the fact that I've, haven't received any formal education, you know, during six years of medical school is already I think you, you know, enough to say, why isn't, why isn't there firstly an actual term and why aren't we talking about it? Why is it not covered?"* (P9)
>
> *"Uh, no. I think our training around that wasn't, um was very broad and very um rudimentary. I think, in my psychoanalytical um training and background, I got a better understanding of repressed memories and which can present in that way in non-epileptic seizures. So, in terms of that, it helps, but not in my base, my basic formal training…I can only imagine some therapists doesn't want to work at a deeper level. What I mean by that is um uncovering layers and or traumatic pasts…I can't speak for other therapists, but I would imagine that it might just be their um either lack of uh training or knowledge of they not, that they might not be willing to take on certain patients."* (P1)
>
> *"…the issue with education…so we do tell our um our undergraduate students about, about the condition, about Functional Neurological Disorders in general. Um it's just, it's a very full programme, and it obviously doesn't get the attention it it should. But again, you know, one could also argue, the majority of of um people who qualify will go out and work as a GP, for example, or become a surgeon, or a chemical pathologist, and there's very little reason to over educate people who go that direction on, on on the condition."* (P12)

5.6.4. HCPs' Relative Level of Knowledge in Practice

This subtheme is based on the HCPs' description of not knowing how to assist their patients. As a result, their patients expressed that they were not being listened to or understood. Five HCPs spoke about their relative knowledge in practice:

> *"…they can sense that you are not taking them that seriously, or that you are kind of, you know, just rushing in to quickly make your note and then go, and you're not really actually taking into account the patient and what is, what is wrong with him…patients know when you are just, you know, trying to tick something off the list and whether you are actually listening and actually actively being present."* (P9)

Some HCPs described making bets or guesses when working with PNES:

> *"…so, again how medicine work, how this process works um is that the neu, and it's an interesting one is that the neurologist makes a diagnosis based on his or her best guess."* (P8)

They also stated that they provided medication to their patients when it was not needed, or found it hard to start the weaning of medication with their patients:

> *"…the patient ends up on a ton of medication, and sometimes even to the extent of being intubated, and it's actually psychogenic."* (P11)

In certain instances, a few HCPs also disclosed that they felt uncomfortable seeing their patients' physical seizures:

> *"I've had one patient who had the seizures in the office, which was, it can be somewhat um hard to see one, um have to react, you're not sure how much you can assist. But so that's been a challenge."* (P1)

5.7. Theme 4: Diagnostic Terms

This theme is based on the terms that the HCPs found inappropriate and stigmatising. They saw these terms as affecting their relationship with their patients, and also resulting in negative communication, which set the premise for future services. It is also based on terms to which they believe the patients would attach negative connotations. In the theoretical framework (Stangl et al., 2019), negative labels would be regarded as negative drivers and facilitators related to larger stereotypes and prejudices being acted upon both culturally and socially, within a medical or therapeutic setting. These labels are also regarded as an intersecting stigma targeted at a patient's health, and as a stigmatising practice based on the

HCPs' discriminatory attitudes. According to Stangl et al. (2019), the outcome from such forms of stigma affects the patient's resilience and advocacy for treatment.

Additionally, this theme is linked to the HCPs' uncertainty about the use of a specific term for PNES. It is noted that multiple diagnostic terms exist for PNES, which can result in a great degree of confusion in relation to both the diagnostic and treatment procedures for both HCPs and patients. Stangl et al. (2019) note that a lack of occupational safety standards and health policy, such as in the case of HCPs not being trained and not knowing how to offer effective diagnostic communication to their patients (in relation to terms being used), are a negative facilitator which enhances stigma. The use of multiple terms can cause patients to feel that they do not have a "right to health", linked to the lack of acceptability within the health organisation and not enough focus given to PNES to narrow down a specific term for the condition. Therefore, this also results in patients internalising negative beliefs (internalised stigma) associated with their condition (Stangl et al., 2019).

5.7.1. Inappropriate Diagnostic Terms

This subtheme refers to terms that are negative or inappropriate, and that were or are currently being used by HCPs (nine out of 13 participants commented on negative terms being used). It is also based on the HCPs' opinions on which terms they believe are not user friendly for patients. These are inclusive of "pseudoseizures" and "Conversion Disorder". "Psychogenic non-epileptic seizures", "non-epileptic seizures", and terms that begin with "psych" were also regarded as problematic due to it suggesting that the patients' seizures are not of a true medical nature. The stigmatising of these terms places a negative label on the patient, which can be demeaning and offer no validation for their condition. The following quotes aid in understanding this subtheme:

> *"So, I think I'm also guilty of using uh pseudoseizures…for a period of time I think that was the term that has been around, and it, it is a cruel term to use. Like you telling your patients you do have a problem, but actually it's a false thing."* (P6)

> *"Non-epileptic seizure disorder, which is sort of the more common one, that also says what it's not, and I mean, that should be one of the key things. You don't start, like if someone's got hypertension, you don't say 'okay, you don't have diabetes'."* (P11)

> *"I've noticed with patients, uh you know, the minute you mention the words psychosomatic, psychogenic, psychosocial, psychological, they kind of close up you*

> *know when you mention it, and and you know it's, it's a, it's a term that shouldn't have any stigma attached to it, but unfortunately, it does."* (P4)

5.7.2. Multiple Diagnostic Terms

This subtheme is based on whether or not the HCPs found the use of multiple diagnostic terms for PNES as problematic. Many HCPs stated that multiple terms are problematic, owing to it causing confusion around what exactly the condition is and the underlying symptoms being diagnosed. They also stated that this resulted in patients not understanding their diagnosis and feeling as if their HCPs are being stigmatising towards them due to not explaining things properly, and the preconceived negative beliefs attached to terms used. Of the 13 HCPs, 10 of them found the use of multiple diagnostic terms to be problematic:

> *"It might create a bit of confusion amongst uh practitioners, but even the um if patients are being told that you have this or that um it might also uh be something that might be misinterpreted by the patient or then by the family members, if they speak to the family about what the doctor told them…is this non-epileptic seizures or functional neurological disorder? Or is it a psychosomatic condition?"* (P3)

> *"I think having lots of names is, is not a good idea. And people think it's not quite the same thing and it can be confusing."* (P2)

> *"It's a bloody hard word! It's just a hard word! What does it mean, explaining what it is and trying to unpack what psychogenic non-epileptic is."* (P7)

> *"If you start adding all sort of other terms, like functional, well, what does functional mean to someone. Again, that might conjure up feelings of um, you know uh, making it up, or faking it, or malingering or whatever, um and or, you know, it's their fault or that kind of thing, um or we don't know what's going on or whatever. Um and so that, all of that's bad in my view…You got non-epileptic seizures, there's nothing wrong with you, off you go. Right. That message I've heard so many times from patients…I can understand why patients when they told that would perceive it in that matter. But the problem is not [that], it's in the way that it is explained to the patients."* (P13)

Three out of the 13 participants believed that people in general should learn to accept and understand terms irrespective of what the condition is called:

> *"I don't see it as an obstacle, or problematic. I think, whatever people want to call it…I think people read things into stuff. So, um I think if people have an understanding of non-epileptic seizures, or what, then whatever you call it, I, they should actually, it should be taken serious and it should be taken um to for what it is. Um so I think it's people's personal affiliations or feeling about it that might make it problematic, but to me, not really, the wording doesn't um change any effect in how I view it…So, then it doesn't really matter what one calls it."* (P1)

Whilst the premise above is justifiable, it may come across as though those three HCPs were not able to see the patient's point of view in relation to certain terms not providing enough sensitivity for their condition. However, with that being said, seven HCPs did state that the use of multiple terms is problematic because of the patients' own prejudicial personal affiliations related to such terms, as seen in the quote below:

> *"And if you talk to patients….they jump to the conclusion that they, they faking it, and it's, it's made up, and so on. Um so I think the, you know, one's got to be careful of terminology, not so much from a professional perspective, but from the perspective of the patient."* (P13)

5.8. Theme 5: Stigma

This theme is based on the forms of stigma associated with the HCPs or their setting. The HCPs spoke about whether or not they believed they were stigmatising towards PNES patients, and if their work environment influenced their stigmatising beliefs. In some instances, the HCPs would not take accountability for their own actions and stated that their colleagues were the actual stigmatising individuals. Many of the HCPs described HCPs, in general, as being dismissive and holding negative attitudes towards their patients. Some HCPs also described the referral process within a medical setting to be dismissive and not helpful to their patients. Additionally, the HCPs stated that occasionally they would find themselves or their colleagues questioning if their patients' symptoms were real.

The information presented within this theme applies to all factors mentioned within the theoretical framework. The drivers present are related to social judgement, blame, authoritarianism, prejudice, fears, and stereotypes formulated by the HCPs which enhance health-related stigma (Stangl et al., 2019). The negative facilitators which contribute to stigma are seen in the HCPs' work environments standards, as well as cultural and social norms which govern their work setting (Stangl et al., 2019). In turn, stigma marking occurs whereby their patients experience a form of stigma directed towards their health, gender, race, and social class. Once the stigma is marked, it then manifests into various stigmatising experiences and practices, such as discriminatory attitudes which are directed towards PNES patients (Stangl et al., 2019). As a result, the outcomes are that patients feel that they are not receiving justifiable care, and the HCPs' work settings do not have enough policies and social protections in place, through which patients receive quality healthcare (Stangl et al., 2019).

5.8.1. HCPs' Personal Stigma towards PNES Patients

This subtheme is based on whether or not the HCPs found themselves to be stigmatising towards their patients. Five HCPs described not knowing if their patients experienced stigma from them:

> *"I have no idea whether they experience stigma from me. Um and I wouldn't be able to answer it, unless one asked the patients, or if they would um mention it in therapy, or if they would complain about the experience of being stigmatised to uh maybe a hospital. But it has not happened and I haven't asked the patients, so I have got no idea."* (P3)

Five other HCPs stated that they believe they are not stigmatising towards their patients:

> *"I luckily don't have that stigma because I am very open, and I also believe that, that all these you know, non-functional and emotional parts of a sickness have a big effect on the actual outcome."* (P9)

Three HCPs mentioned that they were stigmatising towards their patients due to being impatient, not having enough education, and also having an unconscious bias:

> *"…I think maybe when I was a a trainee myself or as an intern, I probably um was impatient with these patients and they probably felt that I wasn't validating their complaints."* (P10)

Some HCPs also mentioned that they did not believe that stigma was persistent or intense for PNES patients in general:

> *"Look first of all, I'm not that aware of, of, of uh stigma being as extreme or frequent…I don't think it's there. I don't think it characterises uh everything about the prevailing clinical understanding and approach to these problems."* (P5)

5.8.2. HCPs' Lack of Accountability

This subtheme refers to how the majority of HCPs (nine out of 13) were not willing to state that they themselves were stigmatising, but stated that they viewed other HCPs as stigmatising. Some psychiatrists and psychologists stated that they perceived neurologists as being stigmatising due to them not having a significant understanding of mental health:

> *"...and even amongst impatient or ignorant neurologists, you know, [they say] this is not a real condition, they wasting our time. Uh well it is a very real condition, and it's not wasting time, we need their expertise, but, but by large that doesn't happen, um mostly that doesn't happen. But that is the seed I think for prejudice."* (P5)

One neurologist stated that he viewed psychiatrists as being stigmatising due to believing that they were inadequately trained:

> *"...so, I don't believe that psych, many psychiatrists are particularly specifically trained in addressing the needs of patients um with Functional epileptic disorder, and there are doubtless particular uh points or aspects of their psychological treatment, uh that patient, uh treating physicians with experience would be able to focus in on as opposed to say a psychiatry registrar who is relatively junior and inexperienced."* (P8)

A few psychiatrists and neurologists indicated that they perceived emergency room physicians to be stigmatising owing to their lack of time, and not prioritising PNES patients:

> *"...I don't think I represent the average um emergency doctor that sees the majority of psychogenic non-epileptic seizures...psychologists and neurologists are people who are trained...they brought to the emergency room and it's like I can't believe you wasted all this hospital time and uh, and an ambulance in a busy area for something that's not even real. There's a reasonable amount of stigma against that."* (P7)

Some psychologists, psychiatrists, neurologists, and the general practitioner viewed nurses as being stigmatising towards PNES patients, because they often perceived them as rushing their duties with these patients and disregarding the condition as a whole:

> *"...If I just think to, you know, how I was called to see the patient. Just depending on the sister who was on duty that night, I might have not been called to assess the patient because they would disregard it as you know, he's just putting on a show."* (P9)

5.8.3. Stigma within a Hospital Setting

This subtheme is based on whether or not the HCPs found a hospital setting to be stigmatising. It is also related to whether the HCPs believed it was beneficial to work within a team and be influenced by the opinions of other HCPs within a hospital. Six of the HCPs stated that a hospital setting, or departments within a hospital, can be stigmatising. They also stated that a hospital can potentially serve as a risk factor for reinforcing stigma due to it fostering an environment for desensitisation:

> *"…I think when there is human beings involved, people are going to be sometimes critical, judgemental, um so there could be and I know in a hospital setting people come up a bit, what is this desensitised, um even to serious conditions, because they have to distance themselves a bit from day in, day out, seeing these um, seeing difficult stuff. So, I think in a hospital setting that could possibly play a role in leading up to stigma because healthcare, some healthcare workers might speak quite loosely or casually about it."* (P1)

Seven of the HCPs claimed that a hospital setting does not contribute towards stigma, and actually serves as a protective factor and guards against stigmatising beliefs:

> *"…we have access to cross examination from different um investigations and lab results, testing that was done, um which, which is helpful to uh get a clearer diagnosis that it's epileptic or non-epileptic. Um but it, teaching in in the hospital environment strongly emphasises uh to not stigmatise in the sense of if you have the diagnosis of non-epileptic seizure, that you should be discarded in terms of that is all you have, that's only psychological, um you don't have epilepsy."* (P3)

Four HCPs also mentioned that whilst a hospital may have an influence on stigma, it is more so dependent on the HCP's personal stigma and team you work in:

> *"…it depends on who your colleagues are, and what sort of a team you have. Um, I mean, some pockets in the hospital are very stigmatising of psychiatric illnesses, and others are much better than it used to be, much better. So, I don't think working in a hospital by definition makes you more judgemental. It can go either way."* (P2)

Six HCPs disclosed that it was negative to work within a hospital team and be influenced by the opinions of others. They also at times felt that they were peer pressured:

> *"…you um gain opinions on patient cases and um by chatting to colleagues and you, especially in the academic setting, patients are presented in groups to the consultant…so, you know, the opinion of one doctor often filters through to others. And, you know, I've noticed in in the way in which these patients are sometimes spoken about is in a more, you know, is in a stigmatised manner, and the doctor who then says no, but the patient really does have something that needs to be corrected is*

> *then, you know, it's you almost feel out of place to to say that…it's in a way, uh peer pressure when it comes to how, how these patients are seen and managed."* (P4)

Nine HCPs, including some who reported a negative experience when influenced by the opinions of others, also recognised that it was beneficial to work in a hospital team due to gaining helpful inputs from other HCPs:

> *"…I think functional seizures are best managed with a team of people, and at least being able to ask opinions of other people…I'd find it very hard being a GP, for example, and manages this myself and not being confident, you know, not being able to access EEGs, and not being able to access a neurological opinion."* (P7)

5.8.4. HCPs' Dismissiveness and Negative Attitudes

This subtheme is based on how the HCPs (10 out of 13) commented on the dismissiveness or discriminatory attitudes typically displayed by HCPs. They described HCPs as being ignorant and disregarding, or treating their patients inadequately. They saw that less of a priority was given to PNES patients, and other conditions were deemed more important. Often, PNES patients were regarded as "time-wasters". The HCPs also viewed some HCPs as being judgemental, and holding negative attitudes towards their PNES patients due to having a psychological problem. The quotes below demonstrate the dismissiveness and negative attitudes shown by HCPs:

> *"…. So immediately, you would just stabilise the patient, um and then disregard the patient… you can leave someone in status epilepticus, you know, and they will sit with brain damage just because you've, you read the notes and you say, oh, no, this is nothing. Saying that I do not think it's nothing…this is just I think the attitude that a lot of people have, as soon as the patient is not, you know, as soon as something is a bit more emotional, a bit more to do with the psyche, lots of physicians kind of, you know, shut off."* (P9)

> *"…healthcare providers um have uh exaggerated senses of their own importance and, and views such patients as waste, as quote wasting their time."* (P8)

Furthermore, the HCPs noted the origins of PNES as partially contributing to negative attitudes in the current care setting. The reason for this is because the discovery of PNES was regarded as historically stigmatising due to it being a problem associated only with women, and those who were hysteric:

> *"...you can see how at pains he is to make his topic legitimate, to make the topic a legitimate object of clinical inquiry because people with Conversion Disorders, I mean, that's why it was called hysteria. This has got something to do with women and it's got somethings to do with the mo-movements of the womb. You know, so it is incredibly paternalistic and impatient, and ignorant attitude towards patients at the time."* (P5)

5.8.5. Referral

All of the HCPs stated that they refer their patients for further care, and/or receive referrals from other HCPs. In addition to being dismissive, the HCPs stated that some HCPs just refer patients for the sake of not wanting to deal with them. Some of the HCPs described the referral process as regularly being one where HCPs do not make enough of an effort to attend to their patients' needs, and do not offer an adequate explanation about the condition to their patients. Subsequently, they reported that patients viewed their HCPs as being stigmatising due to not being caring and helpful. The HCPs also stated that if the previous referral doctor does not make an effort in destigmatising PNES, it can become difficult for them to reverse the effects. The below quotes aid in support for this subtheme:

> *"Well, in terms of healthcare professionals, um you know, the the stigma might come in with uh if it's a psychiatric patient, uh they might tend to uh quickly just refer the patient on to psychiatry, and saying but it's not something that uh needs really medical attention...you find that you know other medical professionals don't have that much patience, work finitely when it's a psychiatric patient...they will quickly then refer, just not try to deal with the patient and send him to psychiatry"* (P3).

> *"...in a state hospital, it's difficult. People are really, really busy. I, I mean, I think it's important that they explain what PNES is in a way that your seizures are real, the cause is psychogenic, and that's the reason we need to send you to my ward, in order to have that part, uh rather than saying your seizures aren't, aren't real...The way that it's explained sometimes by doctors is to the patient not helpful."* (P2)

> *"The neurologists need to have or whoever the referring doctor is needs to put quite a bit of work in destigmatising and um needs to be quite familiar with how to use the right language um to help the patients identify the underlying psychological um drive*

> *towards their condition by the time they see me. If that hasn't happened, then I have a lot of work to do."* (P7)

5.8.6. The Realness of Symptoms

This subtheme refers to how all of the HCPs stated that PNES HCPs, in general, tend to question the extent to which their patients' symptoms are real. The HCPs indicated that PNES is often not seen as a true medical condition in comparison to epilepsy. They also revealed that HCPs find it difficult to work with the condition, owing to believing that there is nothing to correct in their patients. They also believed that some HCPs viewed their patients as either mimicking or faking their seizures, and having a form of voluntary control. Occasionally, they found some of their patients to be dishonest or deceiving. Furthermore, some HCPs stated that their patients display their seizures for means of obtaining attention or secondary gain, or engaging in malingering. The following quotes demonstrate how the patients' symptoms were questioned:

> *"…we're doctors here and we deal with medical issues and this isn't real…it's because it's seen as a psychological issue, and people quickly jump to the conclusion that it's attention seeking and it's put on…you can't say to them okay, this isn't epilepsy, stop it. Um, I think people often don't realise that and so they, they stigmatise it for that reason."* (P2)

> *"…I think when you are not experienced in the field, and you're faced with a patient like this, it is easy to um you know, think as I said earlier, that okay, this patient is doing this for some sort of gain, what do they want? You know, do they want a grant? Are they trying to trick you as a clinician? Are they being dishonest? You know, those are the thoughts that may cross one's mind…it is, you know, easy for the clinician to think of the patient in that way and confuse it with malingering…as human beings, we kind of question somebody who was not being truthful and it comes down to, you know, are these patients being truthful or not…we're all guilty of it as clinicians."* (P4)

> *"…healthcare providers um tend to, just like family and the public, tend to see non-epileptic seizures as a, as, as a simulated condition, not an actual condition. So, they, they, they tend to, I think, believe that it's something that the patient has control over*

> *and it's uh, I think it's often seen as an, as a kind of immature response to certain life circumstances."* (P12)

5.9. Theme 6: Strategies to Reduce Stigma

Many of the HCPs were insightful in suggesting various techniques to reduce stigma, and methods of facilitating positive change in the healthcare field. This is inclusive of offering a means of education and enhancing knowledge, demonstrating equality, explaining and increasing awareness about diagnostic terms, adhering to ethical procedures, and being genuine and showing empathy towards patients. In The Health Stigma and Discrimination Framework, these strategies would be regarded as positive facilitators which alleviate stigma and contribute to the outcomes of justice, access to and quality of health, treatment tolerance, and laws and social protections for both HCPs and patients (Stangl et al., 2019).

5.9.1. Education and Enhancing Knowledge within the Field

This subtheme refers to educating HCPs, as well as patients and their family members about PNES, in order to reduce stigma surrounding the condition. It is also based on further training for HCPs to become sensitised, increasing research within the field, and obtaining inputs from different health professionals. The majority of HCPs (11 out of 13) emphasised the importance of education:

> *"I think it's education on FND [Functional Neurological Disorders], and education on patients with Psychogenic Non-Epileptic Seizures; I think that that's number one, it's, it's educating fellow neurologists, fellow non-neurologists, um colleagues, allied healthcare professionals…Health education, it's um trying to shift mindsets, and, and creating paradigm shifts. Um and uh I think doing, contributing in terms of research, um you know, on-on the subject, so that it's that by, so how we manage these patients is backed by evidence. Um and, ya, I think it's, it's, it's really about um awareness and, and trying to push development in the field to further in South Africa."* (P4)

> *"I think knowledge. Uh so, so, for many things, knowledge is the answer, and, and it's more knowledge about the condition, how it works, how to explain it to patients, and if there's a way we can explain it to patients better."* (P11)

> *"Training um is very important from uh undergrad level, and supervision uh with um registrar interns, um and also research…and then just psychoeducation uh with uh patients and fam-families."* (P3)

> *"Education, education, information, and talking, talking, talking. You know, you invite the neurologists to come to the ward round to listen to what we're saying [psychologists] about the patient they referred, and how we examine what's going on, just, you know, being inclusive, so that people come to see another view of it."* (P2)

5.9.2. Equality

This subtheme refers to treating the patients as 'normal' individuals, as well as treating psychology as an equal profession (eight HCPs spoke about such matters). Some HCPs stated that it was essential to include the patients' view and input in relation to diagnostic and treatment procedures. The HCPs' demonstration of equality towards patients is represented in the quotes below:

> *"I don't treat them any more differently than other patients. I, I think that minimises stigma, that I just see them as another human being. Um in terms of healthcare professionals um if, if I do get to discuss such a patient or have to refer people in general, or meet in supervision, sort of setting where cases are discussed…I would mention that the person was diagnosed with non-epileptic seizures, but I would always go back and try and understand it psychologically, which is also hopefully destigmatising it."* (P1)

> *"…from the hospital side, um and I think this is a nation, if not worldwide, is that seeing psychology as an equal profession, and a valuable uh service, an equal and valuable service. You know, that we, we don't like raise eyebrows if the patient is in the queue to see a psychologist…you could be next to a person with a heart attack, or, or who's been treated for heart attack, and it shouldn't be any different from that you know."* (P6)

5.9.3. Awareness of Diagnostic Terms

As discussed within section 5.7., the use of certain terms can be demeaning towards patients and result in heightened levels of stigma. In order to lessen the levels of stigma, four HCPs stated that it would be useful to explain diagnostic terms to the patients, to enhance their understanding of their condition. The HCPs also mentioned that it would be useful to obtain the patients' input in relation to what diagnostic terms are appropriate to use. The HCPs' sensitivity towards diagnostic terms are seen in the quotes below:

> *"…it's definitely the most important that the patient knows what is, what is their um disease process called and understand what, you know, what is actually happening in their body. Why are they having these, these um epileptic attacks, instead of telling someone you don't have epilepsy. That can lead to a lot of, you know, confusion."* (P9)

> *"I think largely um hearing patients' accounts of how different terms um sounded in their head. You know, words we use or how the diagnosis is relayed, what they understood from it, what leads to negative feelings and whatnot."* (P10)

5.9.4. HCPs' Genuineness and Empathy towards PNES Patients

This subtheme refers to how all the HCPs made an effort to ensure that their patients were treated in a respectful manner, and that their patients felt supported and understood. It is related to the HCPs' understanding of ethical concerns and the importance of engaging in ethical behaviour. It is also based on the HCPs providing a sense of validation of their patients' symptoms. The quotes below illustrate the above-mentioned information:

> *"It's uh the same relationship I would like to foster with all the patients, um and just being sensitive in terms of um different symptoms and ways of expressing distress, internal conflicts, um which might differ for, for different patients. So, the relationship is one again just of building uh positive rapport, and relationship of trust and acceptance, and um also openness. They can talk about you know anything without feeling that they are being judged."* (P3)

> *"All patients should have a good rapport with the doctor. Right, this is the goal. Whether you've got so-called organic disease, or whether you've got functional, there needs to be good rapport. There must be no blaming or shaming…functional disorder, you definitely need to be empathetic as you are with any other condition."* (P11)

> *"It's become quite clear to us over the years that, that this is not something that uh that should be treated differently from any other diagnosis. It's a diagnosis, which is also why we emphasise to, to students both under and postgraduate, that um it's not a diagnosis of exclusion… so I guess what I'm trying to say is, there's no reason for us*

> *to have any different attitudes towards our patients with non-epileptic seizures than to those with epileptic seizures."* (P12)

In relation to the patients' seizures, one HCP stated the following:

> *"The environment is very supportive, um and we don't judge. We don't, you know, tell the person they mustn't have them at all, we understand that it's unconscious, that they can't just decide not to have this…what we try to do is give them lots of attention, lots of emotional attention, and support…we make sure that they can't hurt themselves."* (P2)

Some HCPs stated that it is of essence to explain the diagnosis to their patients in a caring and thoughtful manner to ensure that it is well understood, and to diminish any possible stigma-filled communication. Ethically, they believed that they needed to take responsibility for their actions as health professionals:

> *"There's a very simple script for functional seizures, there's a way in which the message is given and it really doesn't take long to give a very clear message um and an empathic message to a patient with functional seizures, but I think we need to take responsibility as psychiatrists and neurologists who manage this condition."* (P7)

5.10. Chapter Summary

Within this chapter, I provided the key findings of this study. The participants who form part of this study are HCPs who work with PNES patients. They differed in their age, gender, specialisation, and number of years working as a HCP. Upon analysing the data, the semi-structured individual interviews were examined by me through a reflexive thematic lens (Braun & Clarke, 2019); I, in turn, identified various themes and subthemes. These are related to the focus of this study, which is based on HCPs' stigma towards people with PNES. These themes are inclusive of contextual factors that indirectly influenced stigma towards PNES patients, frustrations held by the HCPs, as well as their relative level of knowledge, which potentially increased their stigmatising attitudes. The themes are also based on the use of diagnostic terms, the HCPs' general beliefs about and manifestations of their stigma, as well as methods of reducing stigma. In this current chapter, the six main themes identified were explained and also described in relation to The Health Stigma and Discrimination Framework (Stangl et al., 2019).

In the following final chapter, I will provide a discussion of the findings of this study through the integration of existing literature and further application of the theoretical framework.

Chapter 6: Discussion

6.1. Introduction

Within this chapter, I will further conceptualise the findings obtained from this study according to the theoretical framework deemed appropriate, as well as the literature presented in Chapter 2. Thereafter, I will discuss the limitations of this study and recommendations for future research based on PNES and stigma. Lastly, I will also provide my concluding remarks about this study.

6.2. Conceptualising the Findings using The Health Stigma and Discrimination Framework

As discussed in Chapter 3, The Health Stigma and Discrimination Framework is able to uncover the process through which stigma unfolds within a health-related context (Stangl et al., 2019). It gives attention to mental health and focuses on sociological factors such as economic discrepancies, which may contribute towards influencing sigma (Stangl et al., 2019). The findings of this study demonstrate this framework's applicability, owing to it being able to facilitate one's understanding of how HCPs' stigma manifests towards people with PNES.

6.2.1. Drivers

The first process within the framework is based on the domain referred to as drivers, which negatively increase health-related stigma. It is inclusive of fears towards health conditions, judgement and blame, stereotypes, prejudice, authoritarianism, and lacking awareness (Stangl et al., 2019). Within this study, drivers are seen in the HCPs' frustration towards their patients. This is due to the HCPs' potential prejudice and negative evaluations of their patients, regarding the patients' inability to accept their diagnosis and their overall personality, which in turn drive stigma. Additionally, owing to some HCPs' limited knowledge, it led to them being unable to work effectively and demonstrate a proper understanding of PNES. As a result, due to not being educated enough to understand certain characteristics of the condition, which may seem atypical, they were at risk of being influenced by negative conceptions held by society at large. This is inclusive of the belief that patients with mental illnesses are "crazy" and do not deserve rightful care. Furthermore, stereotyping, which also increases stigma, is viewed in the HCPs use of stigmatising diagnostic terms, in turn, resulting in PNES not being recognised as a proper clinical entity. Overall, the HCPs' dismissiveness, negative attitudes, questioning if their patients' symptoms were real, and lack of accountability, all contribute towards heightening the levels of stigma experienced within a healthcare context.

6.2.2. Facilitators

The next domain is based on facilitators which are either negative or positive factors, and that increase or decrease the amount of stigma experienced by patients (Stangl et al., 2019). The negative factors are related to having a lack of occupational safety standards and health policies in place (Stangl et al., 2019). This is seen in the HCPs’ description of contextual factors based on their lack of accessibility, continuous care, staffing, time, and resources. Due to not being able to offer care which has enough protective procedures in place, patients are likely to feel that they are not valid of lawful care and may view their HCPs as being intentionally avoidant. This may lead to them also believing that their HCPs are stigmatising.

Moreover, some HCPs mentioned that there was a lack of collaboration with disciplines/departments of psychiatry and psychology. The inability to communicate effectively and see the psychological profession as a worthy enough discipline, demonstrates the overall inequality of the healthcare setting. If a HCP from a more “medical” profession is to view psychology in this lesser manner, then it is likely that they will also treat psychological patients in a stigmatising way. Other negative factors seen within the findings are related to the HCPs not receiving a formal education on PNES, and also the uncertainty and inability to agree on a diagnostic term, which in turn shows how PNES is seen as less of priority within an academic and medical setting. Therefore, this also results in HCPs not knowing how to assist their patients, and possibly increasing their negative preconceptions of the condition. Some notable negative facilitators are also related to the social and cultural norms within a healthcare setting. For instance, some HCPs stated that it was negative to work in a team due to feeling pressurised, and some HCPs also disclosed that the referral process within a hospital may be dismissive.

Positive facilitators are viewed in the HCPs’ description of having enough resources, being able to gain helpful inputs from other HCPs, and strategies to reduce stigma. When HCPs have enough resources to assist their patients, they can offer the highest quality of care. Some HCPs noted that working in a team was beneficial as they were able to learn from others and ensure that they were doing what was best for their patients. The HCPs suggested that education and training should be increased, so as to better understand PNES and receive appropriate knowledge on how to work with their patients. They also suggested the need to demonstrate a sense of equality to their patients, and involving the discipline of psychology/psychiatry to create a welcoming atmosphere and increase productivity. Additionally, they mentioned that there should be more awareness of diagnostic terms used, and that HCPs should be empathetic and genuine, so that patients feel respected and supported. Thus, it can be seen that all of these positive factors can minimise the effects of stigma within the healthcare context.

6.2.3. Stigma Marking

Consequently, because of both negative drivers and facilitators being present, we see that stigma becomes marked (Stangl et al., 2019). This is where stigma is applied to individuals because of their health condition, or because of intersecting and perceived differences apparent among a group of individuals. Stigma seen in the HCPs' answers are directed towards those who have a psychological condition, and specifically patients with PNES. HCPs saw PNES patients as having particular personality traits which made them difficult to work with. Due to the HCPs' biased views, they also found themselves questioning if their PNES patients' seizures were real or if their patients had a form of voluntary control. Many HCPs described that those patients with a psychiatric or psychological condition would be quickly referred and disregarded, due to viewing them as "time-wasters". In addition, stigma marked in relation to perceived differences, had to also do with one's social class standing. Some HCPs described their setting as having a lack of resources, and that there was an apparent discrepancy between the public and private sector, which led to the delivery of services for patients being unequal. Another perceived difference was in relation to gender; a few HCPs described the origins of PNES to be patriarchal, and a problem only associated with women.

6.2.4. Manifestations

Following the marking of stigma, it then manifests in a variety of stigmatising experiences and practices (Stangl et al., 2019). Stigmatising experiences refer to discrimination, as well as perceived, internalised, anticipated, and secondary stigma (Stangl et al., 2019). Stigmatising practices include some drivers, and as a whole, refer to negative attitudes, prejudices, stereotypes, and stigmatising behaviours (Stangl et al., 2019). PNES patients may feel discriminated against owing to their HCPs not being easily accessible and providing enough support. They may also feel that their HCPs do not have an adequate amount of knowledge about their specific condition, which makes them feel othered in comparison to patients with physical conditions. By being dismissed and questioned about the realness of their symptoms they may feel inadequate and anticipate similar experiences with other HCPs. Furthermore, some HCPs indicated that certain diagnostic terms are stigmatising due to patients applying the negative connotations associated with those terms to themselves; thereby demonstrating the possibility of patients developing internalised stigma. In analysing some of the HCPs’ descriptions of how patients are negatively looked down upon for needing psychological care, it may suggest that those HCPs who specialise in psychology may deal with secondary stigma and in turn be viewed resentfully. This possibly could prevent future HCPs from working with psychological conditions, and could explain why there is a current lack of staff that specialised in PNES care.

6.2.5. Outcomes

The stigma manifestations then result in a number of outcomes. These are inclusive of having a form of justice, easier accessibility and acceptance within healthcare services, adherence to treatment, advocacy, and the ability to hold the power to challenge stigma (Stangl et al., 2019). From the HCPs’ answers, it is apparent that some of them believed that their relationships with their PNES patients were affected, owing to not being able to be there for them to the best of their best abilities. The HCPs also noted that feeling frustrated with their patients, and not engaging in proper communication with them, led to them ultimately not returning for follow-up procedures. Therefore, this showed the patients’ lack of adherence to treatment or advocacy. The stigmatising attitudes held by the HCPs towards PNES patients, and those with psychological conditions in general, show how there is limited justice and acceptance for mental health patients within healthcare.

With that being said, the HCPs also provided valuable insights in relation to strategies to reduce stigma, which can serve as a means of challenging current stigma. It must be noted, that by the HCPs acknowledging their personal stigma and being aware of the consequences of their actions, it serves as the first step towards recognising that there is a problem that needs to be changed. Some HCPs were able to recognise their stigma, whereas others believed that they were not stigmatising, and some were unsure about their personal stigma. One can only hope that future service provisions for PNES patients will be ethical and efficient due to HCPs’ recognition of their stigma; however, due to lack of consistency among the HCPs’ answers, one cannot truly know the extent of stigma for PNES within the current healthcare system.

By taking into consideration all of the factors discussed above, six main themes together with the subthemes, were identified and explained within the previous chapter on findings. In the next section within this specific chapter, I will integrate the content of the themes with the literature.

6.3. Discussion of the Findings and Literature

As stated in Chapter 2, literature based on PNES and stigma is limited. However, the available literature demonstrates some commonality with the findings obtained within this current study. Within this section, I will discuss how the six main themes identified during data analysis, are linked to the literature available; this is in order to understand HCPs' stigma towards people with PNES.

6.3.1. Contextual Factors

The theme of contextual factors allows one to see how a lack of accessibility and resources, as well as an inability to provide efficient services to patients, can indirectly lead to or influence stigma. da Silva et al. (2020) proclaimed that when there are limited resources, and low care standards and procedures, stigma is likely to heighten, owing to HCPs working in a high-stress environment. There are currently no studies which have specifically looked at the financial burden faced by PNES patients in South Africa, however, studies conducted overseas have indicated that PNES patients experience a great number of costs owing to needing specialist care and equipment (Ahmedani et al., 2013; Magee et al., 2014; Razvi et al., 2012). The same is true for findings obtained from this study, as many HCPs described their services as being expensive and unaffordable for their patients, with many patients also noted as not having enough medical aid. Therefore, this resulted in there being a lack of accessibility for healthcare services.

In addition to resource constraints, Pillay (2019) stated that mental health is not seen as a priority in South Africa, with many individuals not being able to access psychological services. Those individuals who were able to obtain private care benefited from receiving services from a range of HCPs, whereas those who went to public hospitals only received resource-limited treatment (Anderson, 2017; Pillay, 2019; Pretorius & Sparrow, 2015). Pretorius (2016) also discovered that EEG is not easily accessible, and is mainly found within private hospitals. Findings from this current study aid in the support of the previous claims, as many HCPs described their hospitals as not having enough resources in general, and VEEG monitoring being difficult to access and afford. Some HCPs, however, mainly those situated in tertiary hospitals, did state that they have enough resources. In relation to the diagnosis of PNES, a few HCPs noted that there is a delay whereby patients have to wait many years before they achieve an accurate diagnosis, due to limited resources. Brown et al. (2011) also found that patients experience a delay in confirmation of their diagnosis, and that the process of pursuing diagnostic procedures is expensive and time-consuming. Most HCPs within this study also described private hospitals as having more access to resources, where patients were able to benefit from long-term services. Thus, there is an apparent inequality that exists between the public and private sector. Nyblade et al. (2019) explain that such inequality can lead to patients experiencing a means of exclusion from rightful care due to the lack of resources available, which may in turn lead to further stigma in the form of status loss and discrimination.

According to Pillay (2019), there is an acute shortage of South African HCPs that are able to provide psychological treatment. Within this current study, many HCPs commented on how there were not enough psychologists employed within their work setting, and staff in general, to deal with PNES. This was viewed as a barrier in providing care for patients. du Toit and Pretorius (2017), as well as Rawlings and Reuber (2018), declared that often, owing to HCPs' relative knowledge and experience with PNES they tend to gravitate towards other conditions. Additionally, Rivera-Segarra et al. (2018) established that within certain institutional cultures, the association of working with the mentally ill, is frowned upon. Whilst HCPs did not directly state that their association with the mentally ill is negative, some HCPs did indicate that many of their colleagues preferred to work with other conditions. This was due to their lack of knowledge about psychological conditions, and preference to be a physician that deals with conditions that are more organic and physical in nature.

Baslet et al. (2015), Kanner (2010), and Kurcgant et al. (2011) recognised that PNES is often misunderstood owing to a lack of collaboration among the different disciplines that specialise in PNES care, and effective communication that can reduce harmful stigmatising practices. Within this study, a lack of collaboration was seen to exist between disciplines/departments of neurology and those in psychology/psychiatry. Many HCPs commented on how those in neurology wanted to work with "true medical" conditions. Some of them also stated that there were actual physical barriers to the point where they were separated within the same hospital and could not easily access each other for help. A few HCPs also stated that there were problems with communication between different departments, as a result of not being able to access notes, as well as not being able to understand each other's work. Thus, it can be seen, that due to the HCPs not creating a means of collaboration, they were at a higher risk for being stigmatising, as they were unable to offer effective services towards their patients. This may also indicate that they potentially hold prejudicial views towards departments that they do not specifically work in.

Furthermore, Nemade et al. (2020) perceived that those patients who had limited family support were likely to experience an increased level of psychological burden.

Problems with continuity of care were described by some HCPs; they noticed that sending their patients home could be difficult due to them not feeling welcomed within their home environment. This was often a result of patients tending to be othered, and not gaining adequate support from their family and friends, which resulted in them not being able to rely on anyone to help them attend healthcare services.

A few studies noted within the literature review, also identified that HCPs only spent a limited amount of time with their psychological patients, and were not able provide ongoing support (Pretorius & Sparrow, 2015; Rawlings & Reuber, 2016; Robson & Lian, 2017; Whitehead et al., 2013). As a result, the researchers felt that patients did not trust their HCPs, were less likely to return for treatment, and also experienced a sense of isolation (Pretorius & Sparrow, 2015; Rawlings & Reuber, 2016; Robson & Lian, 2017; Whitehead et al., 2013). The same was true for this study, as many HCPs described not being able to offer continuous care to their patients due to not being able to offer follow-up services. The HCPs also stated that they lacked time and were overwhelmed by their workload, which in turn prevented them from performing diagnostic and treatment procedures in a timely and punctual manner. They reported that because of this, their patients may interpret them as stigmatising and as not being willing to make an effort.

In addition, Robson and Lian (2017) found that HCPs discriminate against their patients by not actively listening to their subjective experiences. A few HCPs in this study described that, due to not having enough time to spend with their patients, they sensed that they could not form a proper relationship with them. Some stated that it was just too difficult to sit down with the patient and actually listen to their concerns properly, due to their overwhelming work schedule. Therefore, the HCPs' inability to spend time with their patients is not necessarily discriminatory or purposefully malicious, it is more so having to do with them being unable to balance their workload. However, it may unintentionally lead to patients feeling that they are not a priority for their HCPs.

Furthermore, Audet et al. (2017) claim that owing to hospital HCPs being less accessible, many South African patients with mental illnesses are likely to seek the help of a traditional healer. The reasoning for this is because traditional healers are easier to travel to, readily available, and spend more time communicating with their patients (Audet et al., 2017). The HCPs did describe that they were not always accessible and that some of their patients did have difficulties with travelling to them. They also disclosed that they did not have enough time to spend with their patients, but none of them had mentioned that they believed that their patients pursued the help of a traditional healer. Apart from the apparent need to collaborate with psychology/psychiatry, it is suggested that HCPs should also make an effort to communicate with traditional healers in order be sensitive to the cultural needs of their patients (du Toit & Pretorius, 2018).

6.3.2. HCPs' Frustration with PNES Patients

Robson and Lian (2017) found that many HCPs described working with PNES patients as challenging, intolerable, and overall frustrating, which consequently led to an increase in stigmatising attitudes. The HCPs within this study mentioned that they would become frustrated when having to work with a PNES patient who would not accept their diagnosis. They found that many of their patients struggled to let go of their epilepsy identity, and would want to focus on the physical aspects of their condition. From the literature reviewed, multiple studies have suggested that PNES patients tend believe that their diagnosis is inaccurate; they often approach their physician in order to establish the extent to which their diagnosis is true (Arain et al., 2016; Baslet et al., 2015; Hall-Patch et al., 2010; Lanzillotti et al., 2021; Reuber, 2017). Additionally, Robson and Lian (2017) discovered that patients often feel like outcasts due to having seizures which are caused psychologically, and HCPs choosing to focus on the psychological rather than the physiological components of the condition, which resemble epilepsy. A study done in South Africa by Pretorius and Sparrow (2015), noticed that there tends to be a stigmatising culture in the country, whereby patients believe their PNES diagnosis is inaccurate, and that having a psychological condition is invalid and offensive. Dworetzky (2015) claimed that PNES patients often feel as if they are crazy when they are told that that they do not have epilepsy. This results in complications for future treatment plans (Dworetzky, 2015; Pretorius & Sparrow, 2015).

In addition, the HCPs within this study noticed that their patients were reluctant to speak about the emotional aspects of their condition. Some studies have noticed the same pattern in PNES patients, in relation to them particularly having limited emotional awareness and expression (Goldstein et al., 2000; Urbanek et al., 2014). When patients are not able to respond to treatment appropriately, such as in the case of being able to progress with their emotions, HCPs in turn become frustrated and feel as if their patients are difficult to work with, and unable to benefit from treatment (du Toit & Pretorius, 2017; McMillan et al., 2014; Rawlings & Reuber, 2018). In severe cases, HCPs have been noted as being physically abusive, owing to being frustrated with their patients (Robson & Lian, 2017). In this study, one HCP did mention that HCPs could become aggressive, owing to their patients not wanting to accept their diagnosis.

Many HCPs within this study also disclosed that they could not form proper relationships with their patients due to their resistance. Brown and Reuber (2016a) noted that PNES patients have difficulties with the initiation and maintenance of interpersonal relationships. Often, they approach their therapists with avoidance, insecurity, and anxiety (Green et al., 2017; Wardrope et al., 2019). Owing to the resistance displayed by patients, many HCPs within this study also found that their patients did not want to continue with their treatment. In support of this, Dworetzky (2015) had also found that many patients, after being diagnosed with PNES, were less willing to attend psychological treatment.

Furthermore, PNES was initially linked to hysteria, with patients being regarded as those who would exaggerate the expression of their symptoms. This was a highly stigmatising belief that was initially displayed by HCPs (Alam & Merskey, 1992; Kurcgant et al., 2011; Stefanis et al., 1976, Trimble, 2010). However, it seems as if such beliefs have not entirely changed, as some of the HCPs expressed that they became frustrated when having to work with patients that presented with personality problems. They disclosed that they believed that some of their patients were hysteric and would dramatize their symptoms. Some HCPs also reported that their PNES patients closely resembled those with BPD. Popkirov et al. (2018) viewed BPD in close association with PNES, whereby patients are noted as forming inappropriate attachments and displaying emotional dysregulation.

Additionally, the HCPs stated that as a result of having difficulties in working with their patients, they would tend to project their negative feelings towards them. The HCPs spoke about such negative feelings in a general manner without mentioning any emotions in specific; however, research indicates that HCPs, in general, often respond to PNES patients with anger and confusion (Rawlings & Reuber, 2016).

It appears that the HCPs' frustration may be linked to not clearly understanding the presentation of PNES. Often PNES patients are told that they have epilepsy before they are told that they have PNES (Brown et al., 2011; du Toit & Pretorius, 2017; Rawlings & Reuber, 2018). They thus remain with an epilepsy identity for many years and are treated as an epileptic patient (Brown et al., 2011; du Toit & Pretorius, 2017; Rawlings & Reuber, 2018). One can therefore understand why it may be difficult for them to let go of their attachment towards their epileptic identity. PNES patients are also known to have problems with forming relationships and being able to display their emotions in an appropriate manner (Brown & Reuber, 2016a; Goldstein et al., 2000; Urbanek et al., 2014). By being able to understand such presentations and symptomology, one would expect the HCPs to be more patient and understanding of their patients' personality and difficulty in letting go of their epilepsy diagnosis. In turn, the HCPs would be able to reduce their frustrations, stigmatising attitudes, and potential negative behaviours towards their patients.

6.3.3. HCPs' Relative Level of Knowledge

Multiple studies discovered that owing to PNES being a condition that consists of both psychological and neurological components, it often leads to HCPs becoming confused (Griffith & Szaflarski, 2010; Rady et al., 2021; Reuber et al., 2005; Yeom et al., 2021). Therefore, this also results in HCPs misdiagnosing and mistreating, as well not providing appropriate recognition for the condition as a whole in relation to its symptoms. From the findings obtained in this study, it is evident that the diagnosis of PNES is highly complex. Many of the HCPs described not understanding the condition properly in relation to its symptomology. Often, as a result of their lack of understanding, patients were misdiagnosed. From the literature reviewed, HCPs were frequently perceived to have limited knowledge about symptoms associated with mental health conditions and PNES, resulting in their diagnosis being inaccurate and not accounting for their patients' condition (McMillan et al., 2014; Rivera-Segarra et al., 2019). Particularly within South Africa, Pretorius (2016) noted HCPs as having a limited understanding of PNES and misdiagnosing the condition as epilepsy.

In addition, the HCPs within this study also commented on how they were at times not able to be effective in their communication of the diagnosis and take into consideration their patients' subjective experiences. This in turn affected their relationship with their patients. Similarly, Tolchin et al. (2016) found that due to the complexity of diagnosing PNES, HCPs would not speak to their patients in a considerate manner and were not able to offer an adequate explanation about the diagnosis itself. Rivera-Segarra et al. (2019) declared that when HCPs were regarded as having a lack of knowledge, they were not able to provide an accurate explanation and account of their patients' condition, and could even become neglectful towards their patients as a result. It was thus discovered that when HCPs were unable to actively listen to their patients' concerns, they could be interpreted as discriminatory (Robson & Lian, 2017).

Additionally, Iriarte et al. (2003) stated that a diagnosis can be therapeutic when symptoms are explained to patients in an appropriate manner. When HCPs are able to demonstrate their skilful abilities, and communicate in an open, caring, and understanding way, they are able to lessen the effects of stigma and provide validation of their patients' symptoms (Fouché et al., 2019; Hartwig & Pretorius, 2019; Nyblade et al., 2019). Thus, by the HCPs not being able to engage in effective communication with their patients, it is likely that they were at risk of developing stigmatising beliefs about their patients, and possibly engaging in avoidant behaviours.

Furthermore, the HCPs within this study described EEG equipment as not always being reliable, leading to diagnostic uncertainty. Similarly, some HCPs' perceptions noted within the literature indicate that they tended to view VEEG equipment as expensive and non-compulsory (Iriarte et al., 2003; Sahaya et al., 2012; Syed et al., 2011; Vasta et al., 2018). In some studies, neurologists saw the use of VEEG as essential, whereas psychiatrists and psychologists were more sceptical about its use, owing to the complex aetiological nature of the condition (Baslet et al., 2015; Kanner, 2010). In contrast, neurologists within this study were mainly the HCPs who did not believe that VEEG monitoring was always useful as a diagnostic tool.

The HCPs also commented on how they had particular difficulty in differentiating between PNES and epilepsy. They found it especially hard to identify the exact causes of PNES. As stated previously, PNES is commonly misdiagnosed as epilepsy; Vasta et al. (2018) specifically identified that PNES patients are frequently referred to epilepsy units rather than psychiatric care, which in turn showed that there is a great degree of confusion in relation to the psychological nature of the condition, owing to it not being taken into consideration. Various studies have indicated that 5-20% of patients presented with these conditions concurrently, which led to further complications for HCPs; it would be problematic particularly, when the HCPs were not able to understand their patients' clinical history and seizure presentation (Alsaadi & Marquez, 2005; Benbadis et al., 2001; Griffith & Szaflarski, 2010; LaFrance Jr & Benbadis, 2011; LaFrance Jr & Devinsky, 2002). Additionally, when patients presented with both physical and psychological symptoms, there was a tendency for HCPs to pay more attention towards the physical elements of the condition, due to having more knowledge about such aspects. The hope was that the psychological symptoms of the condition would disappear through treatment of the physical symptoms (du Toit & Pretorius, 2017; Rawlings & Reuber, 2018; Sartorious, 2013).

Within this study, the HCPs did not state that they focused more on the physical elements of PNES. They also mentioned that they would refer their patients to psychological care when necessary. However, they did indicate that many HCPs viewed epilepsy as the true medical condition with more "real" symptoms in comparison to PNES, thus suggesting their potential bias towards not working with PNES patients, and a possible preference for dealing with only epilepsy.

Furthermore, some HCPs within this study stated that they did not receive formal education or training in relation to PNES diagnostic and treatment procedures. The HCPs revealed that courses on PNES did not obtain adequate recognition within an academic or medical setting. As a result of HCPs not being exposed to PNES in general, there was an apparent decline in the number of HCPs that specialise in PNES care. A lack of exposure to PNES was also noted to contribute towards HCPs making limited efforts to educate themselves further about the condition. Naidoo and Bhigjee (2021) specifically perceived South African HCPs as having an insignificant amount of training in relation to identifying and managing functional neurological disorders, which in turn heightened the risk for stigma. Additionally, it was noted that when HCPs have an insufficient amount of skills and training, they are likely to be fearful of their patients and avoid them, further resulting in their treatment being negative and involving below-standard communication with patients (Knaak et al., 2017; Tolchin et al., 2016). As mentioned earlier, the HCPs were not able to engage in effective communication with their patients; however, they did not state that they were purposefully avoidant of their patients due to potential misconstrued beliefs owing to their lack of training. Rivera-Segarra et al. (2018) regarded that at large, within society, mental health was viewed in an unfavourable light, preventing HCPs from further association with working with the mentally ill. This, potentially explains why there is limited exposure to PNES academic courses and specialist HCPs.

Many of the HCPs within this study described not knowing how to assist their patients, particularly in practice, with some patients even noticing the HCPs' inability to work productively. Patients have noted that when they are identified as having PNES, their HCPs often display feelings of misbelief and confusion towards them, and in turn do not provide appropriate services catered to their specific needs (Dimaro et al., 2015; Rawlings & Reuber, 2016). Specific instances described in the literature of HCPs' limited knowledge demonstrated in practice, were seen in them using ambiguous language, and precursor words such as "I think" when communicating with patients. Rawlings and Reuber (2018) found that HCPs would formulate bets on what the likely option was when trying to reach a diagnosis. Within this specific study, some HCPs described that they would sometimes make bets when it came to diagnosing and working with PNES.

A few HCPs within this study also mentioned that HCPs would provide antiepileptic medication to their patients when it was not required. Various studies note the use of antiepileptic medication as being harmful and reducing PNES patients' quality of life (Bodde et al., 2009a; Brown et al., 2011; Lee, 2010; Oto & Reuber, 2018). Often, HCPs mistake

PNES for epilepsy, resulting in them wanting to achieve a reduction of physical seizures rather than the psychological seizures present (du Toit & Pretorius, 2017; Rawlings & Reuber, 2018). LaFrance Jr and Blumer (2010) found that owing to HCPs' limited knowledge about PNES, they tend to spend a large amount of their time tapering with antiepileptic medication until they feel certain.

Furthermore, many studies identified that patients with mental illnesses were often excluded and feared by HCPs, due to being perceived as dangerous and untrustworthy (Helmus et al., 2019; Kohrt et al., 2020; Nyblade et al., 2019; Rivera-Segarra et al., 2019; Ubaka et al., 2018). Some HCPs within those studies also indicated that they were scared of their patients, even when they were considered stabilised (Helmus et al., 2019; Kohrt et al., 2020; Nyblade et al., 2019; Rivera-Segarra et al., 2019; Ubaka et al., 2018). A small number of HCPs within this specific study indicated that when their PNES patients would have a seizure, it was scary to witness. This may have more so to do with their lack of experience and exposure, rather than inherent beliefs that their patients are dangerous.

Therefore, it can be seen that when HCPs have limited knowledge and education, they are unable to understand PNES properly and provide an accurate diagnosis of the condition. In turn, patients may perceive them as unwilling to help or address their concerns successfully. This may also result in HCPs becoming frustrated with their lack of ability to help, leading to them developing stigmatising attitudes towards their patients (Jafari et al., 2020).

6.3.4. Diagnostic Terms

The HCPs within this study described certain diagnostic terms as being problematic, due to them being associated with stigmatising connotations. These were inclusive of "pseudoseizures" and "Conversion Disorder". These terms were seen as problematic due to them not providing validation for the patients' symptoms. This is owing to them being associated with a means of falsehood and resulting in confusion for HCPs about the underlying symptomology. In other studies, "pseudoseizures" were also identified as the preferred term used by some HCPs; it was seen to result in humiliation for patients owing to it being offensive, and implying that their symptoms were not real (Rawlings & Reuber, 2018; Yogarajah et al., 2019). In addition, Asadi-Pooya et al. (2020) claimed that the term "conversion" does not allow for HCPs to fully understand the complex aetiology of the condition, and also results in HCPs being confused due to not knowing on which symptoms to focus.

What is more, is that terms beginning with “psych”, including “psychogenic non-epileptic seizures”, were noted by HCPs within this study to be controversial because it suggested that patients’ symptoms were not viewed as fully medical. Contrary to this, Kurcgant et al. (2011) stated that PNES is able to lessen the stigmatising belief that patients are “crazy”, usually a belief that is linked to the term hysteria. However, Huff and Murr (2021) have provided similar claims in relation to this current study, where they noticed PNES to be problematic due to it defining patients only according to the psychological components of their condition rather than the neurological aspects. Additionally, Asadi-Pooya et al. (2020) stated that by just focusing on the term “psychogenic”, HCPs are likely to only look at the psychological aspects of the condition, instead of the dysfunction apparent in those regions of the brain associated with PNES. Even with the term “non-epileptic seizures”, which is more accepted, the “non” within the term provides recognition of what a patient does not have in relation to epilepsy (Rawlings & Reuber, 2018). Therefore, this results in demarcating and labelling patients according to the characteristics that they do not possess.

As stated previously, multiple diagnostic terms exist for PNES; this can increase HCPs’ level of uncertainty when working with PNES, as well as patients’ confusion due to not exactly understanding their condition. The majority of HCPs in this particular study, found the use of multiple diagnostic terms to be confusing and result in ineffective explanation of the diagnosis. In turn, the HCPs believed that their patients would view them as stigmatising, due to not being able to offer proper clarification of their diagnosis. Some studies have also reported HCPs to be uncertain owing to their inability to agree on a single term for PNES (Rawlings & Reuber, 2018; Sahaya et al., 2012; Yogarajah et al., 2019). Research indicates that the inability to agree on universally accepted terms remains problematic and unsettling, with more efforts needed to agree on a single term which is not associated with stigma (Asadi-Pooya et al., 2020).

More efforts are also required from HCPs in general, in order to explain diagnostic terms to patients in a way that will enable them to gain truthful knowledge about their condition, and reduce their prejudicial beliefs and unrealistic thoughts (Cope et al., 2017; Nyblade et al., 2019). HCPs’ communication of the diagnostic term is important in influencing the patients’ attitudes towards it; therefore, it is of essence that HCPs remain empathetic and show genuine care for their patients’ condition (Fouché et al., 2019; Hartwig & Pretorius, 2019). It is also noted that within South Africa especially, more awareness needs to be created about PNES in general, with attention paid to the sensitivity and inclusion of South African languages. By using South African languages, it would facilitate better understanding of diagnostic terms (Gaede & Versteeg, 2011). However, some HCPs within this study also stated that terms are just labels which need to be accepted and understood, irrespective of what they are called.

Additionally, many of the HCPs within this study, did mention that diagnostic terms are an issue with patients due to them attaching their own prejudicial negative beliefs to such terms. In relation to terms that begin with “psych” specifically, as discussed above, a few HCPs found that their patients were less open to those terms as they were linked to psychology or mental health. As a result, the patients would immediately close up and avoid their HCPs. Therefore, this suggests that they perceive mental health in a negative manner. Rawlings et al. (2018) found that when patients have a psychological condition, they are often faced with discriminatory attitudes from HCPs; this may be manifested through the use of diagnostic terms which are related to widely held stereotypes, such as that patients are faking their symptoms and are time-wasters. Rivera-Segarra et al. (2019) specifically viewed HCPs’ labelling as a form of stereotyping and discrimination; this serves as a means of socially out-casting those with a mental illness. Additionally, Loewenberger et al. (2021) found that patients prefer terms such as “functional seizures” as it limits their association with psychological illnesses and also decreases their level of stigma experienced.

It is noted that in general, when terminology offers an accurate account of patients’ symptoms and experiences, inclusive of a detailed description of the condition’s pathophysiology, patients are then able to form an understanding of their diagnosis and increase their motivation to attend further procedures. It can also result in more positive outcomes, leading to acceptance of the diagnosis within society as a whole, inclusive of the healthcare system, and the community that patients reside in (Asadi-Pooya et al., 2020; Brigo et al. (2015). Therefore, this suggests that more sensitivity should be displayed around patients’ beliefs.

6.3.5. Stigma

The majority of studies on stigma towards those with mental illnesses or PNES, have primarily focused on HCPs’ perceptions regarding the forms of stigma patients may experience from HCPs in general. This current study serves as one of the first to directly ask HCPs to comment on their own personal stigma. Therefore, the study added valuable insights to existing literature by determining whether the HCPs perceived themselves as stigmatising. Many HCPs stated that they were unaware if their patients experienced stigma from them. Some HCPs firmly believed that they were not stigmatising. Three HCPs were able to recognise that they were stigmatising towards their patients, as a result of not being educated, being generally impatient, and holding unconscious negative beliefs about their patients. A few HCPs also expressed that they did not believe that stigma was an existing phenomenon experienced by PNES patients. In a study by Nyblade et al. (2019), which investigated stigma towards the mentally ill within health facilities, they had similarly found HCPs to be unaware of how stigma manifests. In turn, they saw HCPs as not being able to recognise their own stigmatising actions, health policies, and other facilities which were also potentially stigmatising (Nyblade et al., 2019).

Furthermore, some HCPs within this study were more willing to speak about how other HCPs were more stigmatising than themselves. Some psychiatrists and psychologists viewed those who worked outside of psychology to be stigmatising, such as neurologists; they believed that neurologists did not hold an adequate psychological understanding of PNES. Rawlings and Reuber (2018) also found neurologists to be stigmatising as they did not see that treating PNES patients was their personal responsibility. Contrary to this, a neurologist within this study mentioned that he actually believed that psychiatrists were stigmatising because they were inadequately trained. Similar viewpoints were found in some studies, where psychiatrists and psychologists were viewed as having a limited understanding (Baslet et al., 2015; Kanner, 2010). Their lack of understanding was particularly linked to them being less trusting of the results of VEEG when confirming a PNES diagnosis, which led to treatment being ineffective (Baslet et al., 2015; Kanner, 2010). However, these studies did not claim that such HCPs were necessarily stigmatising due to not wanting to rely on the neurological component of the condition. More efforts, inclusive of mutual respect, are required from both neurologists and psychological professionals to ensure vital diagnostic and treatment outcomes for patients (LaFrance Jr et al., 2013).

Additionally, both psychiatrists and neurologists viewed emergency room physicians as stigmatising due to them disregarding PNES patients. Clarke et al. (2014) found that HCPs within emergency departments tend to have feelings of anger and fear towards individuals with mental illnesses. Owing to patients no longer needing to follow-up with such emergency physicians, they found that many of these physicians had a “why bother” attitude (Clarke et al., 2014).

At least one HCP within this study in each profession commented on how nurses were stigmatising towards PNES patients due to their dismissive nature. A study by Ebrahimi et al. (2012) investigated psychiatric nurses’ attitudes towards people with mental illness. They had identified that among 80 nurses, 72.5% had a medium level of stigma towards people with mental illnesses, and 27.5% of them held stereotypical views. This was inclusive of being socially resistant, and believing that patients lack a sense of control and engaged in “sinful” behaviour (Ebrahimi et al., 2012, p. 537). However, the researchers did state that the majority of nurses were empathetic when having a higher knowledge about mental illness (Ebrahimi et al., 2012).

Some HCPs in this study recognised that working in a hospital could lead to an increase in stigma, due to the environment fostering negative beliefs about patients and increasing desensitisation, as well as certain departments being stigmatising. In support, Helmus et al. (2019) discovered that individuals with mental illnesses experience stigmatisation within hospitals to the same extent as the general population (Helmus et al., 2019). Within hospitals, HCPs have the tendency to prejudicially view patients with a mental illness as being unpredictable and potentially dangerous (Knaak et al., 2017). In a study by McMillan et al. (2014), HCPs stated that PNES patients are not always welcomed within neurological departments, and even at mental health clinics, owing to HCPs feeling uncomfortable with treating such patients. Additionally, Sahaya et al. (2013) noted that the hospital environment fostered a culture where HCPs believe that PNES patients are faking their seizures, thus potentially resulting in increased stigma. Moreover, from the literature reviewed, it can be seen that within hospitals in general, a lack of priority is given to mental health conditions, with psychological services receiving less aid (Docrat et al., 2019; Laohathai et al., 2021). Due to this happening at large, it may negatively influence HCPs’ stigmatising attitudes towards psychological conditions and patients’ need for care owing to psychology being disregarded as a whole within the hospital. However, some HCPs within this study have indicated that a hospital setting guards against stigma. Some have also stated that it is not necessarily the setting which has an effect of stigma, it is more so the people that one works with and personal attitudes.

The HCPs within this study presented with mixed reviews about working within a team, as some found themselves pressurised by others’ negative feelings towards patients, whereas others found it beneficial to obtain factual insights from different HCPs where they could challenge their prejudicial views. It is noted that PNES patients have a better prognosis when receiving collective care from neurologists, psychiatrists, and psychologists (Kanner, 2010), thus proposing that working in a team may be beneficial and alleviate the effects of stigma and othering.

Many HCPs within this study described HCPs, in general, to be stigmatising due to holding negative attitudes and being dismissive towards their patients. This was inclusive of HCPs being judgemental, ignorant, disregarding their patients’ symptoms, and viewing other conditions as more important. The huge barrier that still exists today in treatment, as seen from various accounts, is that PNES is not regarded as a clinical entity, which in turn leads to the condition being treated less seriously within healthcare (Baslet et al., 2015; Jafari et al., 2020). Some researchers have regarded HCPs as being unethical owing to them undermining the PNES diagnosis, and being disrespectful and mocking patients (Tolchin et al., 2016). Robson & Lian (2017) similarly found in relation to this specific study, that HCPs tend to be dismissive due to them not listening to their patients' subjective experiences, especially when learning that their patients have psychological trauma. HCPs have been viewed as spending an inadequate amount of time with their patients, and providing a limited amount of support, which has led to their patients feeling isolated (Pretorius & Sparrow, 2015; Robson & Lian, 2017). Kohrt et al. (2020, p. 7) claim that individuals with mental illnesses are often seen as "mad", which results in HCPs being dismissive and not wanting to engage with them.

The HCPs within this study also stated that PNES patients are frequently seen as "time-wasters". The HCPs' negative attitudes were seen as being directly related to the patients having a psychological condition. Studies have also found that those who have a mental health condition are frequently stereotyped as "time-wasters", with the root of such discriminatory remarks being linked to a psychological pathology and the idea that such patients should be able to solve their own problems (Rawlings et al., 2018; Robson & Lian, 2017). As mentioned previously, within South Africa specifically, a stigmatising cultural phenomenon exists towards PNES, regarding it as an invalid diagnosis, owing to it being psychological in nature (Pretorius & Sparrow, 2015). Within society, having a mental illness tends to be seen as shameful, and sometimes such individuals are even feared. This in turn leads to HCPs being dismissive of their patients by clinically resisting them (Knaak et al., 2017; Rivera-Segarra et al., 2018; Ubaka et al., 2018). PNES patients are thus often perceived by HCPs to be taking away time from those who have more "medical" conditions (Annandale et al., 2022; Tolchin et al., 2016).

Other stigmatising attitudes found to be held by HCPs as seen in various studies, are ones that are pessimistic about the recovery of their mentally ill or PNES patients, owing to them believing that their patients are incurable and do not benefit from treatments (du Toit & Pretorius, 2017; Knaak et al., 2017; McMillan et al., 2014; Rawlings & Reuber, 2018; Rivera-Segarra et al., 2019; Tolchin et al., 2016). Contrastively, such stigmatising attitudes were not discovered to be held by the HCPs within this study, with some HCPs even recognising the importance of needing to engage in effective treatment procedures.

In addition, the HCPs within this study mentioned that HCPs, in general, often view themselves as having a higher authority or level of importance in relation to their patients. Helmus et al. (2019) also found that HCPs often view themselves as superior to their patients with mental illnesses. Some studies have stated that PNES patients are generally seen as inferior within society, which leads to them avoiding more "superior" authorities such as HCPs, due to not wanting to feel less worthy of help or not wanting to be treated coercively (Robson & Lian, 2017; Simons et al., 2018; Ubaka et al., 2018). Overall, HCPs' dismissiveness and negative attitudes have been found to result in them personally feeling morally distressed and not providing quality care (Kohrt et al., 2020).

Furthermore, the origins of PNES were also seen to have a slight stigmatising influence on the work of some of the HCPs within this study, with a few still believing the condition to be associated with only women and those who are "hysteric". As noted within the literature, PNES was initially seen as a form of hysteria, whereby patients were viewed as dramatizing their symptoms (Breuer & Freud, 1955; Kurcgant et al., 2011). Thus, this led to the stigmatising attitude that PNES patients were inappropriately emotional and did not deserve adequate care (Alam & Merskey, 1992; Kurcgant et al., 2011; Stefanis et al., 1976; Trimble, 2010). Whilst PNES is still known to occur more frequently in women today, this is often a result of them having to deal with more traumatic experiences than males (Benbadis & Hauser, 2000; Reuber et al., 2007), rather than the paternalistic idea that PNES originates in women owing to it being a "problem of the womb". The origins of PNES are therefore extremely controversial, owing to the influence that they can potentially have on a HCP's work, suggesting that further education is required to reduce outdated information and beliefs.

The referral process described by HCPs within this study was one where HCPs in general, were seen to not take into account their patients' concerns. Thus, HCPs pass on PNES patients to the next HCP in order to not deal with them directly. The HCPs stated that this phenomenon was highly dismissive, and that often there was not enough time to offer an adequate explanation about the condition to patients. In turn they perceived that many patients may view HCPs as stigmatising as a result of the referral process. Some HCPs also commented on how it becomes difficult to work with patients when a previous referral doctor does not make enough of an effort to destigmatise the condition, leading to patients being reluctant to receive care from all HCPs. From the literature reviewed, in relation to referring patients, the contrary has been found, as HCPs were seen as being reluctant to make a referral for patients. Yogarajah et al. (2019) specifically, found that GPs felt uncomfortable when needing to refer their PNES patients to psychiatry, suggesting that they did not want to be associated with patients with psychological conditions. Sartorious (2013) established that many HCPs avoid making referrals in order to lessen their perceived stigmatisation of working with patients with mental illnesses. Even though the HCPs within these two studies (Sartorious, 2013; Yogarajah et al., 2019) did not refer their patients so as not to deal with them, they still did not want to be known as mental HCPs and viewed their association with their patients in a negative manner. Within healthcare, the avoidance of mentally ill patients is viewed as being extremely stigmatising and dismissive (Nyblade et al., 2019).

Additionally, a frequent pattern identified by HCPs within this study was that many PNES HCPs, in general, tend to question and assess whether their patients' symptoms are real. This is owing to PNES often being perceived as a non-medical condition, with no true symptoms in comparison to epilepsy. Some HCPs also stated that they viewed their patients as dishonest and deceiving. Patients were often viewed as faking their seizures or engaging in a form of voluntary control. They also stated that at times they believed that their patients only displayed their seizures to obtain a form of secondary gain or to engage in malingering. Multiple studies have similarly found that many HCPs believe that their patients have control over their seizures, and are actually faking them (Pretorius & Sparrow, 2015; Robson & Lian, 2017; Sahaya et al., 2012; Tolchin et al., 2016; Yogarajah et al., 2019). Some studies have shown that HCPs believe that patients present with seizures for means of obtaining a secondary gain, such as to obtain a disability grant or form of support, and to avoid their current responsibilities (du Toit & Pretorius, 2017; McMillan et al., 2014; Rawlings & Reuber, 2018).

According to patients' personal accounts, they have declared that HCPs often view them as engaging in a form of malingering or trying to gain attention (Robson & Lian, 2017). HCPs choose to specifically focus on symptoms that they do not have in comparison to epilepsy, leading to them feeling othered (du Toit & Pretorius, 2017; Rawlings & Reuber, 2018; Robson & Lian, 2017). Patients have stated that they are also often faced with feelings of doubt, anger, and misunderstanding by HCPs when identified as having PNES. Therefore, this results in their symptoms being perceived as unreal by HCPs, which is highly stigmatising (Rawlings & Reuber, 2016).

6.3.6. Strategies to Reduce Stigma

Whilst insightful information was obtained from the HCPs in regards to stigma displayed towards people with PNES, many of the HCPs were also able to provide strategies on how to reduce the effects of stigma. The most prominent strategy provided by the HCPs was that of increasing education and knowledge about PNES. This was inclusive of educating themselves and fellow HCPs. Naidoo and Bhigjee (2021) declared that stigma levels are heightened due to South African HCPs having a limited amount of education and training on PNES. When HCPs lack knowledge, they often believe that the condition is too complex to treat and in turn they become frustrated, and are more likely to view their patients in a negative light (Tolchin et al., 2016). This is inclusive of HCPs believing that their patients are faking their symptoms, and overall being pessimistic about their patients' recovery (Knaak et al., 2017; Tolchin et al., 2016; Yogarajah et al., 2019). Therefore, it is acknowledged that only when HCPs are provided with anti-stigma education and more knowledge about the condition in general, will they be able to realise their own prejudicial biases and beliefs, which in turn will decrease their stigma (Knaak et al., 2017).

Education about PNES for patients and their family members was also seen as vital, in order to challenge current stigmatising beliefs and create factual knowledge. Research shows that PNES patients who had a lower level of education, as well as limited family support, inclusive of family members reacting in unnecessary ways towards their condition, subsequently experienced a heightened level of psychological burden (Nemade et al., 2020). Thus, this demonstrates the apparent need for patients and their family members to be educated.

The HCPs also suggested that more sensitivity training should be performed. As mentioned before, PNES patients have certain personality traits which cause frustration for HCPs. However, their personality and inability to form typical interpersonal relationships is often a result of their childhood trauma (Popkirov et al., 2018). When HCPs are better equipped to understand this and demonstrate sensitivity towards their patients' experiences, their patients in turn are able to achieve a better prognosis (Popkirov et al., 2018).

The HCPs also indicated that more research should be conducted to enhance knowledge within the field. It was noted that during certain time periods, such as the 1980s, there was a paucity of research being conducted on PNES. However, with new research emerging, it had resulted in notable discussions among psychiatrists, which had led to the realisation that hysteria was a problematic diagnosis owing to it causing confusion, and patients being misdiagnosed with epilepsy. This led to more interviews and tests being conducted, which allowed researchers to become attuned to cognitive and psychological factors related to PNES (Henrichs et al., 1988; Kurcgant et al., 2011; Vanderzant et al., 1986; Wilkus et al., 1984). Therefore, this demonstrates the need to conduct and evaluate current findings through ongoing research. Recent research by Annandale et al. (2022) also supports the need for more research to be conducted on PNES, in order to move away from outdated and misconstrued information.

Additionally, in relation to education, the HCPs believed that it would be beneficial to obtain different HCPs' perspectives and learn from each other. A problem that still exists today, is that PNES is a complicated condition to diagnose and treat, owing to it resting on the border between neurology and psychiatry. Researchers believe that HCPs within these disciplines should communicate better and learn from each other's practices in order to enhance their knowledge and reduce prejudicial views (Baslet et al., 2015; Kanner, 2010; Kurcgant et al., 2011). Particularly, neurologists' knowledge is needed in both diagnostic and treatment procedures, so as to assist with coexisting neurological abnormalities. This means that it is important for them to maintain a connection with psychological professionals in order to produce the best outcome for their patients (LaFrance Jr et al., 2013).

The next strategy which the HCPs suggested, was that of treating PNES individuals as regular human beings or just like other patients, without any perceived differences or the need to treat them differently. It is recognised that patients often view themselves as social outcasts due to having a psychological condition, and HCPs being discriminatory towards them (Robson & Lian, 2017). As a result, they are more likely to experience a heightened level of perceived and internalised stigma. It is therefore crucial for patients to be treated in a respectful manner, similar to those who have a clear physiological condition, for means of enhancing equality and lessening stigma (Rawlings et al., 2018; Robson & Lian, 2017)

The HCPs also stated that they believe it is important to obtain the patients' opinions in relation to diagnostic and treatment procedures. This is to ensure that the patients are contributing significantly towards their care, and to also alleviate the HCPs' superiority. Brown et al. (2011) and Jordan (2007) claim that when HCPs pay attention to their patients' accounts of their symptoms, it can lead to obtaining an accurate diagnosis, and better results for the patients overall.

Furthermore, the HCPs believed that more effort should be made to construe psychology an equal and worthy profession. What is frequently seen is that there is a lack of communication and collaboration between medical departments such as neurology, and the departments of psychology and psychiatry, as discussed within the contextual factors (Baslet et al., 2015; Kanner, 2010; Kurcgant et al., 2011). This is sometimes the result of psychology being viewed as less than within the entire healthcare system. It is thus necessary for these departments to understand each other's practices better and see each other as equal, in order to lessen the transferability of stigma from psychological professionals to psychological patients (Baslet et al., 2015; Kanner, 2010; Kurcgant et al., 2011).

As mentioned previously, the use of particular diagnostic terms can be problematic due to them being associated with negative stigmatising connotations. To reduce the impact of the stigma associated with such terms, the HCPs suggested that it would be best to explain diagnostic terms to patients for means of enhancing their understanding of their condition and to eliminate stigmatising biases. They also stated that it would be beneficial to obtain the patients' input about their feelings towards diagnostic terms. It is recommended that HCPs should be more aware of the pejorative use of terms because not only does it lessen the effect of stigma, it can also increase the understanding of the signs and symptoms of the condition, and lead to the condition being recognised with clinical significance (Kurcgant et al., 2011; Trimble, 2010).

Moreover, diagnostic terms are recognised as shaping both HCPs' and patients' negative attitudes, as certain terms, such as PNES, tend to be related to the idea that patients' seizures are "fake" or that they are "crazy" (Kurcgant et al., 2011; Rawlings et al., 2018). As discussed, PNES also defines a patient according to the characteristics they lack in relation to epilepsy, therefore being invalidating (Huff & Murr, 2021). It is thus important to use terms which do not contain stigmatising connotations, provide recognition for the patients' symptoms, and enhance their acceptance within healthcare for the purpose of reducing stigma as a whole (Asadi-Pooya et al., 2020). Loewenberger et al. (2021) and Annandale et al. (2022) identified that patients prefer the terms "functional seizures" and "dissociative seizures", as it provides more validity to their symptoms and reduces their possibility of stigma. Therefore, this suggests that formulating names for PNES should proceed in that manner.

The HCPs within this study also commented on the importance of treating their patients in a respectful and empathetic manner, where they felt supported and understood for means of reducing possible stigma-filled encounters. This is based on the HCPs' recognition for the need to act in an ethical manner. It was inclusive of explaining the diagnosis to PNES patients in a helpful manner, which provides a means of acceptance for their symptoms. It is noted that many HCPs demonstrate discrimination towards their PNES patients by not genuinely listening to their concerns and experiences, leading to their patients developing negative internal feelings (Rawlings et al., 2018; Robson & Lian, 2017). Patients often also describe feeling alone and without support from their HCPs, which in turn has lowered their trust in HCPs (Pretorius & Sparrow, 2015; Robson & Lian, 2017; Whitehead et al., 2013). It is thus crucial for HCPs to become more aware of their stigmatising actions and engage in ethical behaviour in order to reduce the undesirable effects of stigma. Nyblade et al. (2019) stated that showing empathy and genuine care towards patients enables them to progress positively on both a personal and healthcare level, with HCPs being perceived as less stigmatising.

6.4. Limitations and Recommendations for Future Research

There were various limitations which were encountered by me, the researcher, within this study. Firstly, the sampling method which was selected was inclusive of both purposive and snowball sampling. The initial sample group was based on contacts that my supervisor was aware of; they had specialised in the diagnosis, and/or treatment and management of PNES within two hospitals in the Western Cape. These contacts were then asked to share the contact details of other HCPs that may be interested in participating. Thus, the sampling strategy was limited as it relied upon connecting with different HCPs and their connections, leading to potential bias and preventing contact with other possible participants. However, this was an exploratory study and rich information was obtained. Data saturation was achieved upon sampling 13 participants, thus demonstrating that the sampling procedure was effective. It is recommended that future studies should include a wider variety of HCPs by potentially obtaining a database of different specialists from various hospitals. It may also be beneficial to consider using voluntary response sampling, as different hospitals could be informed about the study, and multiple HCPs could choose to volunteer their participation.

Secondly, the sampling group was not representative of all specialists working with PNES patients. This was owing to the inability to obtain nurses for the study as a result of their busy work schedule or them not responding to communication, despite continuous efforts of making contact. Additionally, from the participants’ answers, it is evident that both nurses’ and emergency room physicians’ opinions would have added valuable insights towards this study, owing to many HCPs believing that they hold stigma towards people with PNES. It would therefore be beneficial to investigate the truth behind these claims in future studies. Although, it must be noted that the purpose of qualitative research is not to be representative so as to generalise findings, but rather to provide an in-depth account of experiences, which has nevertheless been achieved by this current study. It is recommended that for future studies on PNES and stigma, different HCPs that work with PNES patients should be approached and included, in addition to those who formed part of this current study; this is in order to obtain different perceptions.

Finally, a potential limitation which was identified was the use of qualitative semi-structured interviews. Owing to the sensitivity of speaking about stigma and the possible social desirability to appear favourable, the personal nature of the interviews may have hindered HCPs from being open and fully disclosing information. Nevertheless, valuable and detailed information on the HCPs' perspectives and experiences were obtained through using qualitative interviews. However, it may be useful for future research to include the use of quantitative surveys in order to increase anonymity and encourage the revelation of further information.

6.5. Conclusion

This study aimed to explore HCPs' stigma towards people with PNES, with particular attention paid to understanding the HCPs' experience and knowledge of PNES, discovering the attitudes they hold towards PNES, and exploring their views on how stigma manifests towards people with PNES. Owing to the explorative nature of the study, information related to the aims and objectives were revealed through the apparent themes which were identified.

This was inclusive of contextual factors that indirectly influence stigma. Such factors illustrate important issues that exist within the South African context. Often patients are not able to easily access and afford the services offered by HCPs. There is an apparent disparity in relation to the resources and skills available to HCPs in the private and public healthcare sector, which leads to an unequal social class division. In addition, by not being able to offer continuous care, having limited time, and lacking staff, HCPs are not able to offer efficient services to their patients. This can result in patients viewing their HCPs as stigmatising, owing to feeling as if they are not receiving their rightful care. Furthermore, the disciplines/departments of psychiatry and psychology tend not to be treated seriously within a hospital environment; there are even physical barriers in the hospital that serve as a means of separation and that affects communication. Therefore, this also increases the stigma faced by both psychological HCPs and patients.

Furthermore, many HCPs described feeling frustrated with their patients owing to them not being willing to accept their PNES diagnosis. It is suggested that HCPs should be more understanding of their patients' inability to accept their diagnosis, as patients are often told on multiple occasions that they have epilepsy, and thus it may be hard for them to let go of it, owing to it becoming an entrenched part of their identity. Additionally, the HCPs also found it difficult to work with certain patients because of their personality, and in turn they found themselves projecting their negative feelings onto their patients. HCPs' frustration with

PNES patients can have a potentially dangerous effect owing to it being a driving force for hostile and discriminatory behaviour, as well as the development of prejudicial attitudes.

In addition, when HCPs do not have adequate knowledge about PNES, they find it difficult to diagnose the condition and differentiate it from epilepsy. They may also not know how to assist their patients in general, which may lead to further frustrations. It is noted that when HCPs have limited knowledge, they are less able to guard themselves against stigmatising beliefs. Many HCPs also commented on how they had not received formal training, thus suggesting that more efforts should be put into further education for PNES.

Moreover, an identified continuous problem that heightens stigma for PNES patients is the use of specific diagnostic terms. Some terms allude to the idea that patients' symptoms are of a false nature such as "pseudoseizures", whereas more neutral terms such as "non-epileptic seizures" are also problematic as they define a patient according to not having epilepsy. The use of multiple terms can result in confusion for both HCPs and patients. Not being able to identify a single term for the condition, shows the lack of priority in viewing PNES as a diagnostic entity.

In relation to the HCPs' personal beliefs about their own stigma or stigma towards PNES patients in general, they presented with mixed opinions. Some HCPs reported that they were not stigmatising, whereas others believed that they were stigmatising at times. Some also did not know if their patients felt stigmatised by them. Interestingly, a few HCPs also stated that stigma was not profound or even present for PNES patients. Many HCPs also readily stated that other HCPs were stigmatising rather than themselves. It is recognised that only when one is able to acknowledge one's own stigmatising beliefs, that positive change can follow.

Furthermore, a hospital environment was regarded by some HCPs as contributing towards stigma due to it enhancing desensitisation towards patients. A few HCPs stated that working in a team was difficult, owing to being negatively influenced by the opinions of others. However, some HCPs also found the hospital environment to lessen the effects of stigma as they were able to cross-check matters with other HCPs and obtain factual information when working in a team. There were also those who believed that a HCP's own personal attitudes and beliefs were more likely to contribute towards stigma, than the setting itself.

Other forms of stigma noted from the HCPs, was that of HCPs, in general, being dismissive, and holding negative attitudes towards their patients; this was often owing to believing that other conditions were more important, and that psychological conditions did not deserve the same effort of care. The origins of PNES were also seen to be rooted within a stigmatising culture and still have a slight influence on the work of some HCPs today. Whilst the referral process is necessary within a hospital, many HCPs believed that HCPs make referrals for the sake of not wanting to attend to their PNES patients. A few HCPs mentioned that this is often challenging, as they have to destigmatise the previous referral doctor's actions. Additionally, HCPs also tend to question whether their patients' symptoms are real, due to frequently believing that there is a faking component or that patients are trying to obtain a means of secondary gain.

However, the HCPs within this study did provide useful strategies for means of reducing stigma, inclusive of increasing education about PNES, treating PNES patients on an equal level with respect, creating awareness about diagnostic terms, and being genuine and empathetic towards patients. All of these strategies can be seen as relating directly to the information above about how stigma manifests, thus serving as a form of guidance on how to alleviate the effects of stigma. By the HCPs being able to offer such insights, it demonstrates their capacity in wanting better outcomes for their patients, and that not all HCPs are intrinsically stigmatising.

This study is one of the first within South Africa to explore stigma towards people with PNES. The findings obtained serve as a foundation from which future researchers can draw insightful information. Through this study, I strived to create awareness about stigma towards PNES patients, which will hopefully in turn lead to the positive effect of decreasing stigma as a whole.

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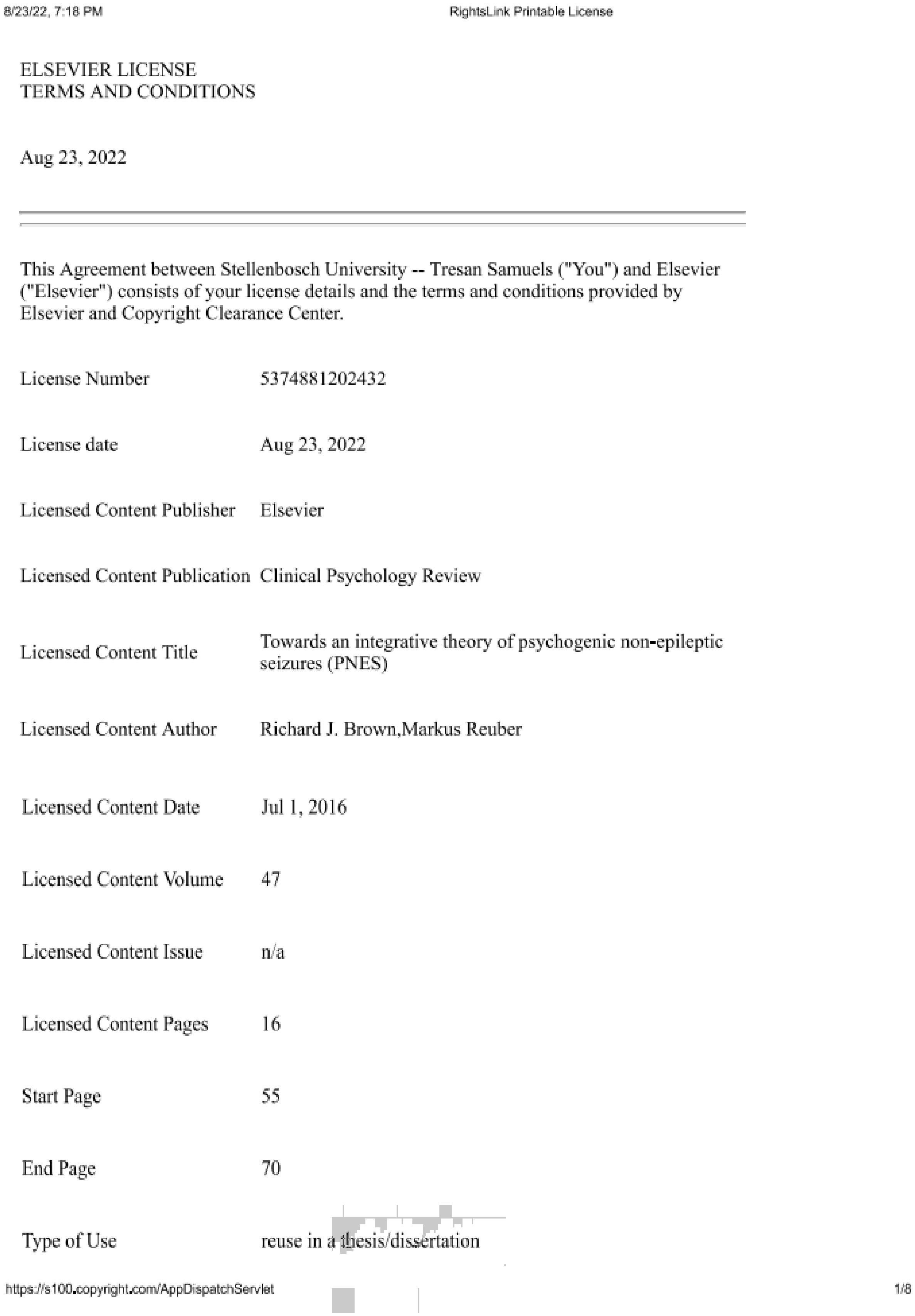
Appendices

Appendix A: Permission to Use Figure 1



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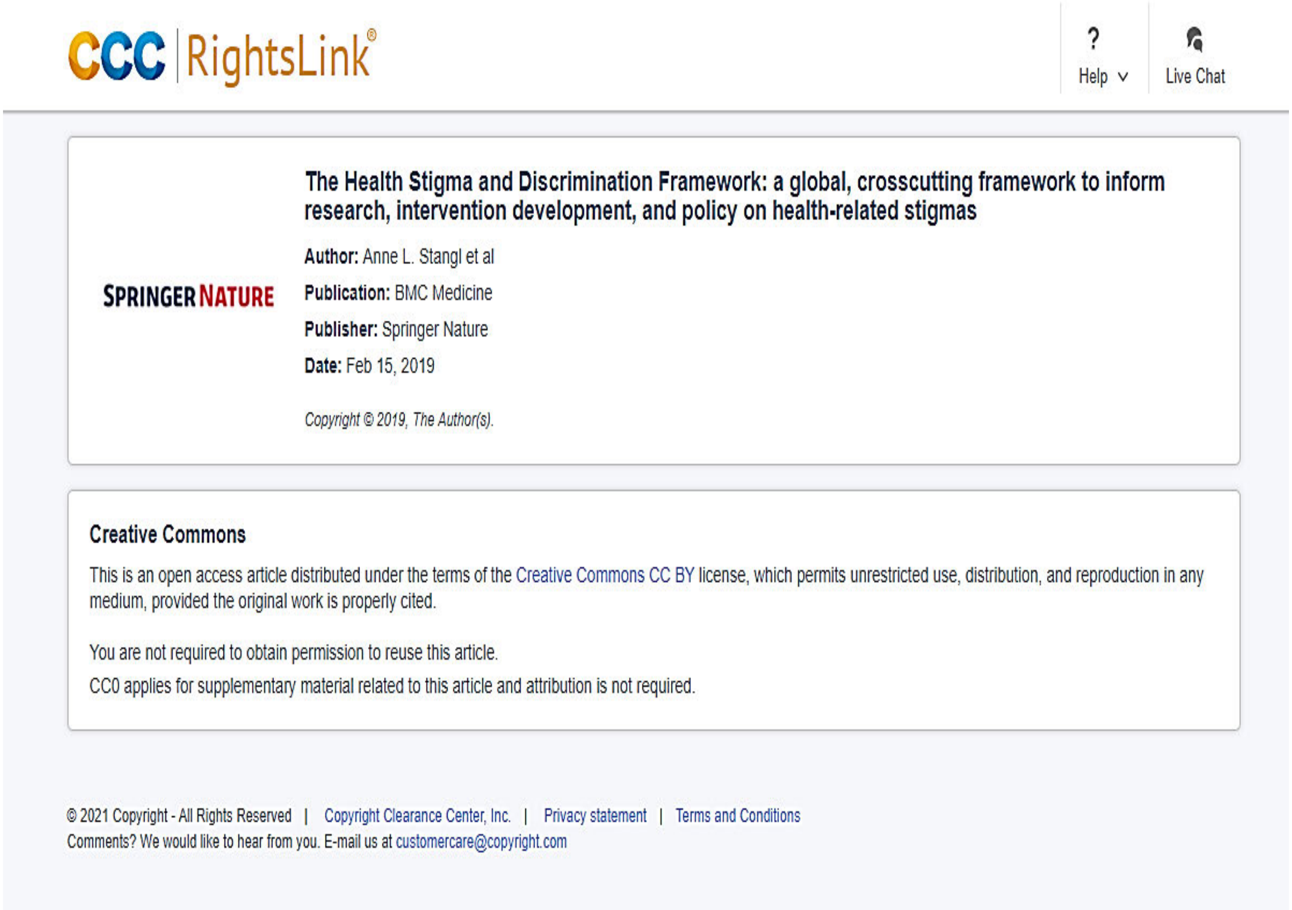
Appendix B: Permission to Use Figure 2



The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas

Author: Anne L. Stangl et al

Publication: BMC Medicine

Publisher: Springer Nature

Date: Feb 15, 2019

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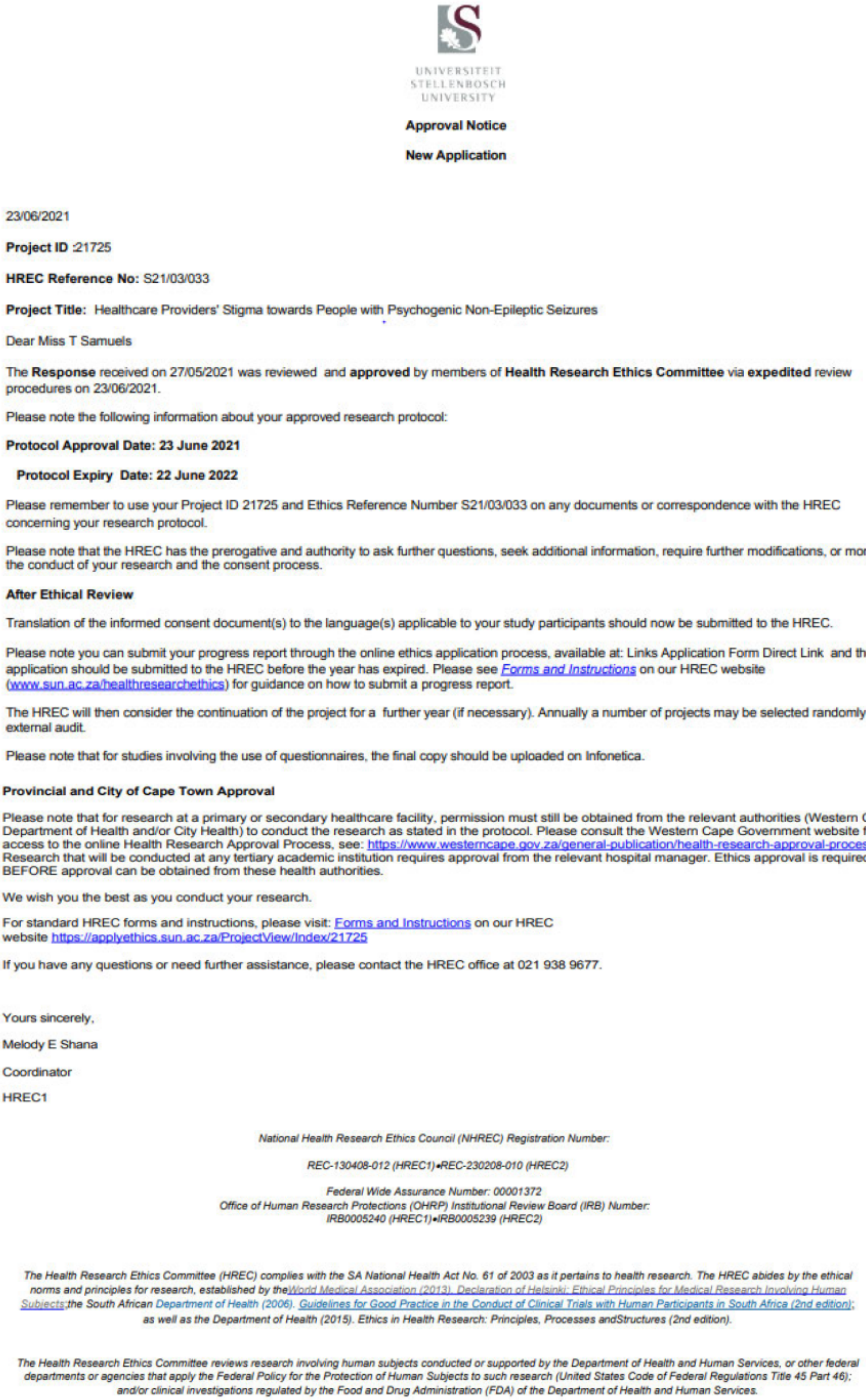
Appendix C: Health Research Ethics Committee Approval Letter



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Approval Notice

New Application

23/06/2021

Project ID :21725

HREC Reference No: S21/03/033

Project Title: Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures

Dear Miss T Samuels

The **Response** received on 27/05/2021 was reviewed and **approved** by members of **Health Research Ethics Committee** via **expedited** review procedures on 23/06/2021.

Please note the following information about your approved research protocol:

Protocol Approval Date: 23 June 2021

Protocol Expiry Date: 22 June 2022

Please remember to use your Project ID 21725 and Ethics Reference Number S21/03/033 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/21725

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Melody E Shana

Coordinator

HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

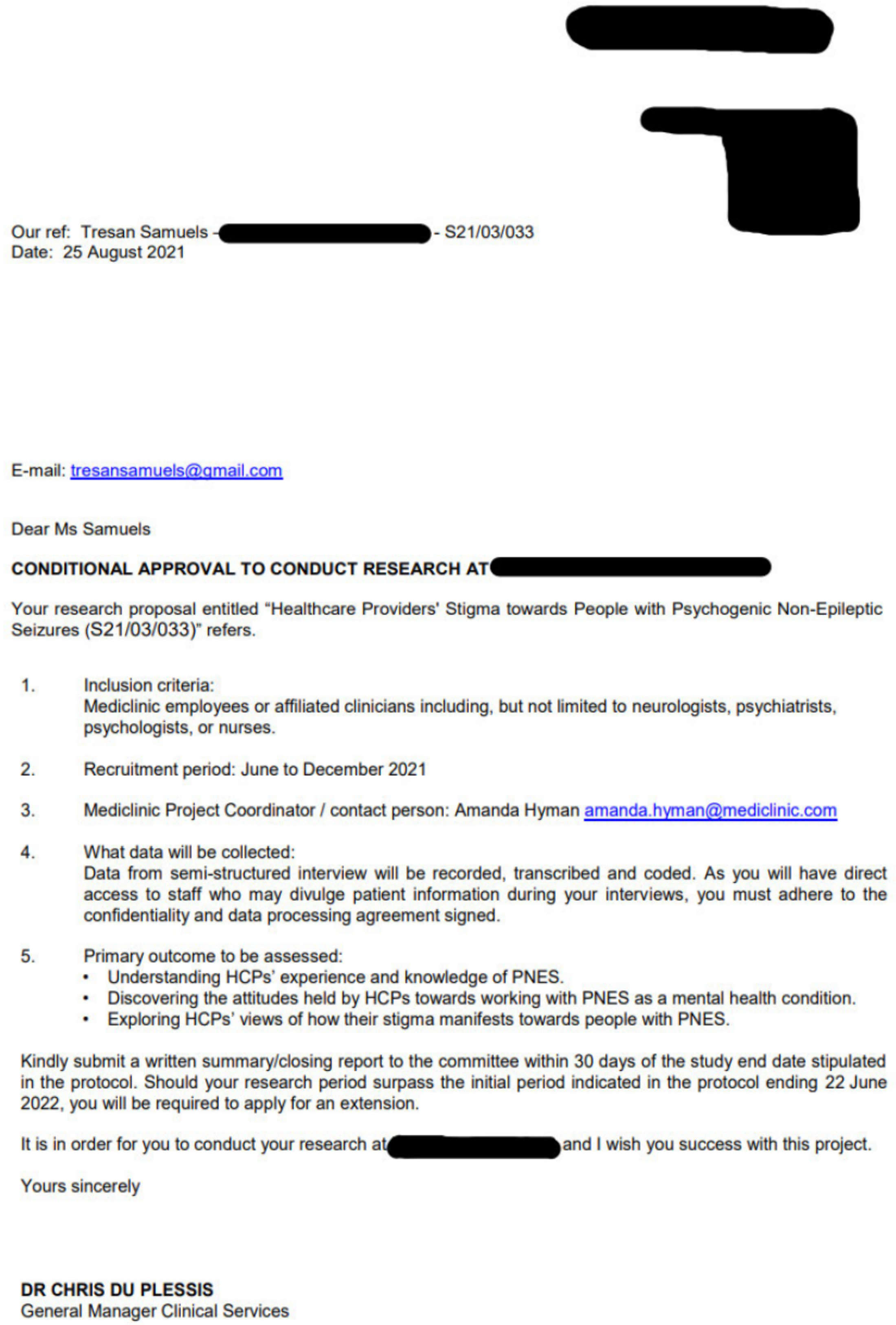
Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes andStructures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix D: Institutional Permission from a Private Hospital in the Western Cape

Please note that the location(s) of practice are blurred out in black within the approval letter to ensure confidentiality.



[redacted]

[redacted]

Our ref: Tresan Samuels - [redacted] - S21/03/033
Date: 25 August 2021

E-mail: tresansamuels@gmail.com

Dear Ms Samuels

CONDITIONAL APPROVAL TO CONDUCT RESEARCH AT [redacted]

Your research proposal entitled "Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures (S21/03/033)" refers.

1. Inclusion criteria:
   Mediclinic employees or affiliated clinicians including, but not limited to neurologists, psychiatrists, psychologists, or nurses.
2. Recruitment period: June to December 2021
3. Mediclinic Project Coordinator / contact person: Amanda Hyman amanda.hyman@mediclinic.com
4. What data will be collected:
   Data from semi-structured interview will be recorded, transcribed and coded. As you will have direct access to staff who may divulge patient information during your interviews, you must adhere to the confidentiality and data processing agreement signed.
5. Primary outcome to be assessed:
   - Understanding HCPs' experience and knowledge of PNES.
   - Discovering the attitudes held by HCPs towards working with PNES as a mental health condition.
   - Exploring HCPs' views of how their stigma manifests towards people with PNES.

Kindly submit a written summary/closing report to the committee within 30 days of the study end date stipulated in the protocol. Should your research period surpass the initial period indicated in the protocol ending 22 June 2022, you will be required to apply for an extension.

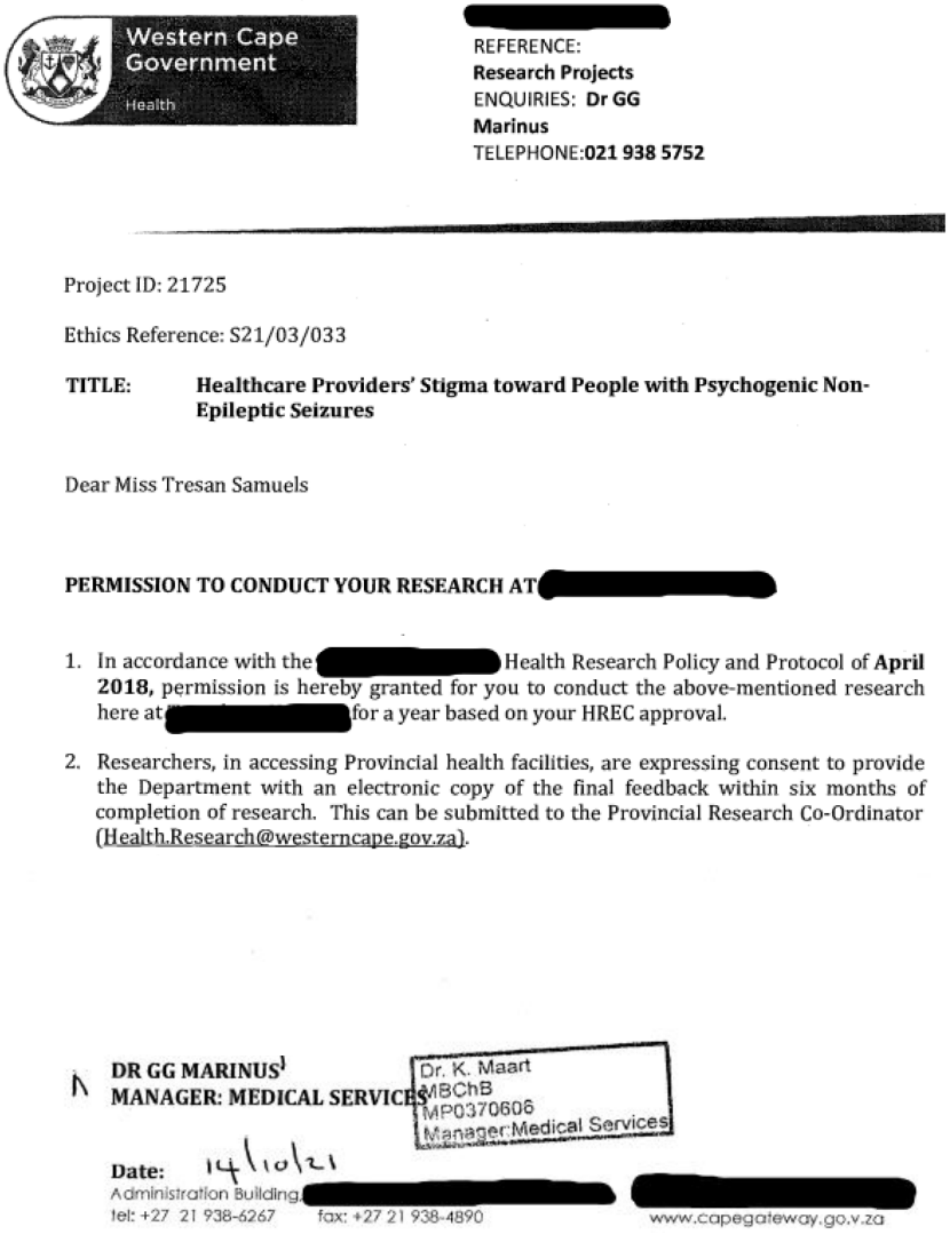
It is in order for you to conduct your research at [redacted] and I wish you success with this project.

Yours sincerely

DR CHRIS DU PLESSIS
General Manager Clinical Services

Appendix E: Institutional Permission from a Public Hospital in the Western Cape

Please note that the location(s) of practice are blurred out in black within the approval letter to ensure confidentiality.



Western Cape Government
Health

[redacted]
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Project ID: 21725

Ethics Reference: S21/03/033

TITLE: **Healthcare Providers' Stigma toward People with Psychogenic Non-Epileptic Seizures**

Dear Miss Tresan Samuels

PERMISSION TO CONDUCT YOUR RESEARCH AT [redacted]

1. In accordance with the [redacted] Health Research Policy and Protocol of **April 2018,** permission is hereby granted for you to conduct the above-mentioned research here at [redacted] for a year based on your HREC approval.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

DR GG MARINUS
MANAGER: MEDICAL SERVICES

Dr. K. Maart
MBChB
MP0370606
Manager:Medical Services

Date: 14/10/21

Administration Building [redacted] [redacted]
tel: +27 21 938-6267 fax: +27 21 938-4890 www.capegateway.go.v.za

Appendix F: Email Invitation to Healthcare Providers

Dear Healthcare Provider,

My name is Tresan Samuels, and I am a MA Psychology (thesis only) student at Stellenbosch University. My supervisor for my master's research project is Dr Chrisma Pretorius. I would like to invite you to participate in my study titled: Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures (PNES).

Please take some time to read the information provided within this letter of invitation, which will clarify the details of my study. It is important to note that participation in this study is completely voluntary, and that you have the right to decline to participate. You may also withdraw from this study at any time you wish to do so, should you choose to participate. There will be no negative consequences posed to you either personally or professionally, should you choose not to participate.

This study has been approved by Stellenbosch University's Health Research Ethics Committee. This study will be conducted according to accepted and applicable national and international ethical guidelines and principles, including those of the International Declaration of Helsinki.

The main aim of this study is to explore healthcare providers' stigma towards people with PNES. Should you choose to participate in this study, you will be requested to complete a biographical information sheet and a once-off semi structured interview according to a time and place that is convenient for you. Due to the potential restrictions as a result of the COVID-19 pandemic, the semi-structured interview will either take place in-person or via an online platform such as Microsoft Teams or Zoom, depending on the current circumstances. The duration of the interview is expected to be between thirty to sixty minutes. Through the semi-structured interview process, I would like to determine your knowledge and experience with working with PNES, discover the attitudes you hold towards the mental health condition, PNES, and understand your own views on how healthcare providers' stigma manifests towards individuals with PNES.

Please note that any information that you share with me throughout this study will remain confidential. Your identity will not be exposed as I will use pseudonyms. Throughout the duration of this study, all data will be stored in a secure place such as my supervisor's cabinet, which will be locked. All electronic files will be password-protected and encrypted. Only my supervisor and I will have access to the data involved in this study. The data will be stored for a period of five years, and thereafter be appropriately discarded. However, with your permission, the data will be shared anonymously within a peer-reviewed accredited journal and/or with other students.

Owing to participation being completely voluntary, no remuneration will be provided for participating in this study. You will also not incur any expenses from participating in this study. I will confirm with you if you require any assistance with accessing a stable internet connection and online platform, and are in need of internet data, prior to the commencement of the interview, should you choose to take part in the study and prefer to conduct the interview online. Thus, data provisions will be made if necessary.

Should you wish to participate in this study or have any questions, please contact me, Tresan Samuels, via email or telephone If you choose to participate, I will provide you with an informed consent form requesting your confirmation and permission for participation within my study.

Thank you for considering to participate in my study.

Yours Sincerely,

Tresan Samuels
Principal Investigator

Appendix G: Biographical Information Sheet

Please note: I will ensure that I remain respectful and that your anonymity will be protected.

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Name and Surname: ………………………………………………………………………
Age: ………………
Gender: Male/ Female/ Prefer not to share/ Other*
If other, please specify: ………………………………………………………………….
Title: ……………………………………………………………………...........................
Home language: Afrikaans/ English/ Xhosa/ Zulu/ Other*
If other, please specify: ………………………………………………………………….
Email address: ……………………………………………………………………………...
Contact number: …………………………………………………………………………
Your qualifications: …………………………………………………………...………
What is your specialisation/ Do you specialise in any specific field?: ………………………
…………………………………………
For how many years have you been working as a healthcare provider: …………………..

Appendix H: Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF RESEARCH PROJECT:	
Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Miss Tresan Samuels	**Ethics reference number:** **S21/03/033**
	PI Contact number:

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the principal investigator any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

The purpose of this study is to explore healthcare providers' stigma towards people with Psychogenic Non-Epileptic Seizures (PNES). Specifically, I would like to formulate an understanding of your knowledge and experience with working with PNES, determine your attitudes towards the condition, and identify your views on how healthcare providers' stigma manifests towards individuals with PNES. Healthcare providers that are regarded as specialists in PNES at the Unit for Epilepsy at a private hospital, and Department of Neurology at a public hospital in the Western Cape, will be approached first via an email invitation, as they have access to video-electroencephalogram monitoring and are able to provide an accurate diagnosis of PNES. Due to the use of snowball sampling, other hospitals containing healthcare providers that specialise in PNES may be used within the sample, should they be identified as a potential participant by other participants. Depending on the circumstances, interviews may occur on an online platform e.g., Zoom or Microsoft Teams, or in-person according to your preference.

Why do we invite you to participate?

You were approached as a possible participant because you are able to provide valuable insights on healthcare providers' stigma towards people with PNES, due to your own experiences with working with patients with PNES.

What will your responsibilities be?

If you agree to take part in this study, you will be asked to complete a biographical information sheet and partake in a once-off semi-structured interview. The semi-structured interview will be conducted according to a time and place that is suitable for you. This is also inclusive of online platforms, e.g., Zoom or Microsoft Teams. The semi-structured interview may range from a minimum of 30 minutes to a maximum of 60 minutes. It will contain broad open-ended questions based on stigma and PNES. The semi-structured interview will also be audio-recorded with your permission for means of data analysis.

Will you benefit from taking part in this research?

By taking part in this study, you will be able to add to the field of research and raise awareness about PNES. A limited amount of research exists globally on PNES, and within South Africa specifically there is a lack of studies that have primarily examined stigma in relation to PNES. Your participation may contribute to identifying strategies to diminish stigmatisation towards individuals with mental illnesses, and highlight the importance for healthcare providers to remain ethical in their conduct.

Are there any risks involved in your taking part in this research?

This proposed study is a medium-risk study as the research topic is based on stigma, and may be sensitive for participants to reflect on. However, only your opinions and general views based on stigma and PNES will be required. Please note that I will be non-judgemental in the interpretation of your perspectives and conduct member checks to ensure that I have reflected your opinions accurately. If you experience any emotional distress during the interview process, you will be referred to a healthcare professional at Welgevallen Community Psychology Clinic who will provide you with appropriate counselling services free of charge. You may also experience discomfort owing to the inconvenience of the time that is required for your participation. However, I will ensure that I will work according to your availability, and conduct the interviews according to a place and time that is suitable for you.

If you do not agree to take part, what alternatives do you have?

Not applicable.

Who will have access to your records?

The original data will be stored for a period of five years, after which it will be appropriately discarded. However, my supervisor, Dr. Chrisma Pretorius, and I would like for the anonymised data of this study to be published within a peer-reviewed accredited journal. Any information that you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring your anonymity and confidentiality through the use of pseudonyms. If you choose to not answer a question, this will not affect you in any negative manner either personally or professionally. The final research report will be available online, and will be used to formulate a journal article. My supervisor might also want to use the semi-structured interviews where all identifying particulars have been removed for other students to work on. You will have the opportunity at the end of the document to provide permission for your data to be used in such a case or not.

Even though it is unlikely, what will happen if you get injured somehow because you took part in this research study?

Not applicable.

Will you be paid to take part in this study and are there any costs involved?

No remuneration will be provided for your participation, as the interviews will be conducted according to a time and place that is suitable for you. You will also not incur any costs from participating in this study, such as that of needing to travel to a specific setting. Internet data provisions will be made upon your request if you wish to conduct the interview online.

Is there anything else that you should know or do?

- You can contact Tresan Samuels at if you have any further queries or encounter any problems.
- You can also contact the researcher’s supervisor, Dr. Chrisma Pretorius at if you have any queries or encounter any problems.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study doctor has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I ……………………………….……….. agree to take part in a research study entitled: Healthcare Providers’ Stigma towards People with Psychogenic Non-Epileptic Seizures.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary,** and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) ....…........…………….. on (*date*) …………...………..

....

Signature of participant Signature of witness

Declaration by investigator

I …………Tresan Samuels…………………………… declare that:

- I explained the information in this document in a simple and clear manner to … ……………………………….
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.)*

Signed at (*place*) ......……………………………… on (*date*) ……………….

....

Signature of investigator Signature of witness

Permission to have all anonymous data shared with journals:

Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study. When this study is completed, we would like to publish the results of the study in a peer-reviewed journal. Most journals require us to share your anonymous data with them before they publish the results. Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

Permission for sharing information with other investigators:

Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study.

Once we have completed the research that we are planning for this research project, we would like to store your information. Dr. Pretorius may want to give other students working under her supervision access to the data that has been collected. The students will not have access to the original data set. They will only have access to the anonymised data. Therefore, we would like to ask for your permission to share your anonymised data with other students.

Tick the Option you choose for anonymous data sharing with journals:

I agree to have my anonymous data shared with journals during publication of results of this study

☐ Signature____________

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

☐ Signature____________

Tick the Option you choose for sharing information with other investigators:

I do not want my sample and/or information to be shared with other investigators

☐ Signature______________

OR

My sample and/or information may be shared with other investigators for further analysis and future research in a field related to research on PNES.

☐ Signature______________

Appendix I: Semi-Structured Interview Schedule

A. Knowledge, Understanding, and Experience with PNES

1. What is your experience thus far as a healthcare provider with working with the condition, PNES?

2. How do your patients with PNES differ from your patients with epilepsy, if at all?

B. Attitudes towards Diagnosing, Treating, and Working with PNES Patients

3. When working with the condition PNES, how would you describe your level of confidence?
   Probe for psychiatrists and neurologists- how would you describe your level of confidence with diagnosing PNES?
   Probe for psychiatrists, psychologists, and neurologists- how would you describe your level of confidence with treating patients with PNES?

4. Who do you believe is best suited to diagnose and provide treatment for patients with PNES, and why?

5. What are the barriers or challenges you face when working with patients with PNES?

6. Tell me about the resources/lack of resources in your experience when you work with patients with PNES.

7. How would you describe your relationship with patients with PNES?

C. Stigma

8. What are your views as a healthcare provider on stigma towards patients with PNES based on your interaction with these patients?

9. In what ways do you think PNES patients experience stigma from you as a healthcare provider, if any?

10. What do you think is the main reason patients with PNES face stigma from healthcare providers like you?

11. Do you believe that being in a working environment such as a hospital reinforces stigmatising beliefs for healthcare providers like you, and could you please provide a reason for your answer?

12. What would you recommend to counterbalance the effects of stigma within a healthcare setting or from you as a healthcare provider?

D. Conclusion and Snowball Sampling

13. Are there any additional comments that you would like to make?

14. Do you possibly know of any healthcare providers that may be interested in participating in this study. If so, would you mind if my supervisor, Dr. Chrisma Pretorius follows up with you, or could you please share the email invitation to other healthcare providers that could possibly participate in this study?

Appendix J: Reflexive Diary Entries

This section offers a description of the healthcare providers that were interviewed within this study. Each participant is referred to by his/her participant code (for example, P1 refers to participant one), in order to ensure confidentiality. Demographical information obtained from the healthcare providers, are mentioned. My personal reflections, as the primary investigator, on the interview process with each healthcare provider, are also disclosed.

P1

My first interview was with a 44-year-old male clinical psychologist, who has 12-years of experience working as a healthcare provider. This interview was conducted over Zoom. Owing to it being my first interview and having to reschedule the interview twice, I found the process to be a bit nerve-wracking, but the prompt communication and eagerness of this healthcare provider made everything flow easily. He was able to provide me with a thorough understanding of PNES from a psychoanalytic point of view, mainly surrounding repressed trauma and character pathology. Even though I had researched and obtained information for my literature review based on the psychoanalytic/psychodynamic treatment of PNES, his practical insights were truly valuable. He offered a glimpse into how therapy and proper understanding from a healthcare provider can alleviate the effects of stigma. He also pointed to the idea that individuals should learn to take all mental health conditions seriously, irrespective of its diagnostic terms. I found this to be quite interesting in relation to PNES, and how its vast name iterations tend to be problematic. At the end of the interview, he stated that he decided to be a part of this research because he believes it is important, and that more awareness needs to be given to PNES. His genuineness towards my research had made me excited to conduct future interviews and discover more about PNES and stigma.

P2

My second interview was with a 63-year-old female clinical psychologist, who has been working as a healthcare provider for 32 years. This interview was also conducted over Zoom. Whilst it is difficult, in general, to connect with someone over a technological/online platform, I found the discussion between me and this healthcare provider to occur in an open and friendly atmosphere. She was very knowledgeable and provided detailed answers to my questions. Although the interview did not last the full expected duration, I felt that I was able to grasp a great amount of important information from her. She was the first healthcare provider to provide the realisation that patients with PNES are often stigmatised due to the misbelief that they are faking their seizures. She also emphasised the difficulty in having to explore the emotionality of PNES, owing to the trauma associated with the condition. I truly admire this healthcare provider for her work and the insights that she holds. I was glad when she stated that my research is needed within the healthcare field, and that she would like a copy of the report.

P3

I found my third interview to be slightly intimidating, as it was my first with an older man (55-years-old), with 30-years of experience working as a healthcare provider. He had expertise in both clinical psychology and psychiatry. Despite my initial intimidation, the interview ran smoothly and was also conducted over Zoom. His answers were detailed and he showed a vast amount of knowledge about the field that he is within. The part of the interview that I enjoyed the most was how this healthcare provider took into consideration the South African context in particular, and how it has an influence on PNES patients. I found it extremely valuable to obtain information from a direct source, as there is limited literature based on PNES in South Africa. This healthcare provider was quite stern and did not have any further comments to make, but his smile at the end of the interview reassured me that it was a mutually pleasant experience.

P4

The fourth interview was my first one with a female neurologist, in particular. This healthcare provider was fairly young (35-years-old), and has been working for 11 years. This interview was also conducted over Zoom. I thoroughly enjoyed this interview and found it easy to connect with this healthcare provider. She had a clear understanding of the effects of stigma towards patients with PNES, and provided me with a sufficient number of examples. Whilst the previous healthcare providers had spoken about the importance of a multidisciplinary team, this specific healthcare provider was able to shed more light about the importance of neurologists and neurological equipment in diagnostic procedures. She also was able to recognise the importance of other healthcare providers in treatment procedures for PNES. This was inclusive of psychologists providing therapy. However, she emphasised the need for neurologists to remain active in treatment and provide reassurance to PNES patients. This was in order to eliminate the effects of abandonment, which is a common pattern identified in patients with PNES patients, owing to their traumatic experiences.

Towards the end of the interview, this healthcare provider reflected on her own experience of conducting research on PNES, and was able to see the need of this current research. This in turn, served as a form of encouragement and motivation for me to approach my research in a positive manner.

P5

My fifth interview was with a 59-year-old male clinical psychologist, who has 30-years of experience working mainly within a hospital environment. This interview was conducted over Microsoft Teams. Owing to my own personal distressing circumstances at this specific period of time, having gone through a loss in my family and experiencing a motor vehicle accident, I found my mental and physical capacity to be limited. The empathetic nature of this healthcare provider was completely genuine, and appreciated by me, as I had to reschedule the interview to another time after I gained enough emotional strength. He claimed that he is not as specialised in the field of PNES, and may therefore not know everything, but that he does work with PNES patients. Irrespective, I still obtained valuable information from this healthcare provider. He was the first to refer to the history of PNES and the link to the current "problematic nature" of the condition. I was also amused by how he found this condition to not necessarily be linked with stigma. Overall, he was extremely talkative, and therefore this interview was the longest I had so far. His kind and bubbly attitude made the interview process an enjoyable experience.

P6

My sixth interview was with a 55-year-old female clinical psychologist, with 23-years of experience working as a healthcare provider. I had initially spoken to this healthcare provider telephonically, to clarify the details of my study and to set up a date and time for the interview. In our initial communication she showed a sense of excitement for finally being able to talk to me, owing to our previous efforts being unsuccessful due to her busy schedule. Her enthusiastic nature made me look forward to our upcoming interview. She was the first healthcare provider that I interviewed who showed somewhat of a true sense of the difficulties of working as a healthcare provider in South Africa. This was due to where she was positioned, and the lack of resources that she had in comparison to the settings where the previous healthcare providers had worked. We had initially begun the interview over Zoom, but owing to her hospital’s faulty internet connection, we could not pursue the interview further on this platform. This healthcare provider was extremely friendly and was willing to do whatever she could to be a part of this interview, such as going to her personal residence to conduct the interview. I reassured her that it was fine, and that I did not want her to go out of her way. I therefore suggested to her that we should conduct the interview telephonically, and that I would initiate the call so that she did not have to experience any costs. She agreed that the telephonic interview would be easier. At the end, I was able to learn a lot about PNES, especially in relation to hospital dynamics, from this healthcare provider.

P7

My seventh interview was with a 44-year-old female psychiatrist, who has been working for 22 years as a healthcare provider. This interview was conducted over Microsoft Teams. It was the first interview where I felt somewhat uncomfortable. This was owing to the healthcare provider’s criticism of my research and slightly defensive nature in relation to the topic being on stigma, as she believed that she did not fit my sample. I tried my best to reassure her of any concerns that she had about the research from an empathic stance. I explained that I was just trying to understand her experience as a healthcare provider working with PNES, rather than accusing her of being stigmatising. I also provided her with relevant literature I had obtained to demonstrate the relevance of the research that I was conducting. I did not proceed further with the interview until she felt settled and comfortable to continue. Despite these initial concerns, she had continued the interview and was able to provide me with relevant information about PNES from a psychiatrist’s point of view. This was inclusive of commenting on how the use of language, and working according to the patients’ limits and not pushing them to explore matters that they are uncomfortable with is important in destigmatising. I was taken aback by this interview as I had not experienced one like this before in terms of having to defend my research. However, looking back at it now, it was actually a positive experience that taught me how to expect the unexpected and stand my ground as a researcher without feeling that I did not know enough. It also showed me how to look at criticism in a constructive and realistic manner. I made sure to debrief about this interview with my supervisor, who, in turn, guided me on how to handle a situation like this, should it happen again. However, my supervisor did assure me that I had done the best within my capabilities at that time.

P8

The next interview, being the eighth one, was with a 60-year-old male neurologist, who has been working as a healthcare provider for 30 years. Prior to the interview, I was in a bit of a tricky situation with this healthcare provider, due to him not being too fond of the format of the informed consent form. However, I had apologised for the inconvenience and had helped him to fill it in. We then proceeded with our interview over Microsoft Teams, after those matters were sorted. Owing to his frustration with the consent form, he came across as very stern in the beginning, but as we started to communicate further, he was easing into the interview and opened up more. I also felt that my previous interview had helped me to deal with the difficulties of this current interview. He demonstrated a great amount of knowledge about the divisions that exist in treatment for patients with relation to one's economic circumstances. He was also one of the first healthcare providers to comment on how some patients may have a Functional Neurological Disorder for the means of obtaining a disability grant. This is consistent with the findings seen in the PNES literature. At the end of our interview, I thanked him for his time and had apologised again for the initial inconvenience. He laughed it off, and said that it was no problem and that he was actually sorry for being rigid.

P9

My nineth interview was my first one with a general practitioner in particular, a 26-year-old female, who has been working as a healthcare provider for 2 years. This interview took place over Microsoft Teams. Even though this HCP was the youngest, she was still able to offer detailed and valuable information. She also was the first healthcare provider who mentioned her experience working within an emergency room setting, and thus was able to offer a new insight. From our interview, I was able to learn more about, how at entry level, education and training is not sufficient for PNES, which in turn influences a healthcare provider's work ethic. This healthcare provider showed a genuine interest in wanting to learn more about PNES and mental health. She suggested that more general practitioners should start showing a genuine interest in relation to their patients' mental healthcare. She also looked forward to reading the results of my study, and stated that it was an honour to be a part of it. Overall, this interview was fairly enjoyable and definitely gave me a new outlook on the knowledge that different healthcare providers have surrounding PNES.

P10

My tenth interview was with a 43-year-old female neurologist, who has been working for 11 years as a healthcare provider. This interview had initially begun over Zoom, however, towards the middle of the interview the audio was broken. We then continued the interview telephonically. I found this healthcare provider to be soft-spoken and very kind. The way in which she shared information was in a knowledgeable and empathic manner. She also shed light on how important EEG equipment is for neurologists when it comes to making a diagnosis. She was one of the very first healthcare providers who was not afraid to speak about her lack of expertise and potential stigma as a healthcare provider, as well as how she has changed from early experiences in her career. She had also introduced me to other resources and reading material that neurologists often rely on when it comes to working with PNES. I had gone through this material in my own personal time, and found it very helpful in relation to my study and understanding PNES as a condition. After conducting an adequate number of interviews, I must admit that the authenticity of this healthcare provider was truly refreshing.

P11

My eleventh interview was with a 41-year-old male neurologist, with 18-years of experience working as a healthcare provider. This interview was conducted over Microsoft Teams. Prior to having finalised a date for the interview, he had thanked me for taking on my study topic and believed that it definitely needed more research. This in turn made me feel enthusiastic to conduct my interview with him. This healthcare provider had a casual nature to him, which made the interview one where communication flowed easily. The part of the interview that stood out the most to me was his comment on how some patients malinger. Whilst other healthcare providers did speak about malingering and secondary gain, this healthcare provider described a vivid experience of such matters involving a potential gun threat. It had taken me aback because I did not hear of malingering to the extent he had described. However, it reminded me of the realistic nature of the South African context and the actions that people are willing to take in order to gain some benefit, due to the poor economic stances that they live in. This interview definitely had me thinking more about patients in South Africa, and what it entails to be a healthcare provider. From my point of view, whilst I do believe that healthcare providers need to be held accountable for their negative actions towards patients, I also think that one is quick to judge healthcare providers for not offering good care or being stigmatising. Yet, at the same time if a healthcare provider’s life were to be threatened, then how can one necessarily blame them for their inconsistencies in healthcare. With that being said, I also think that more resources, financial, and other helpful services should be offered to South African citizens who are struggling, so that they do not need to pursue actions of malingering.

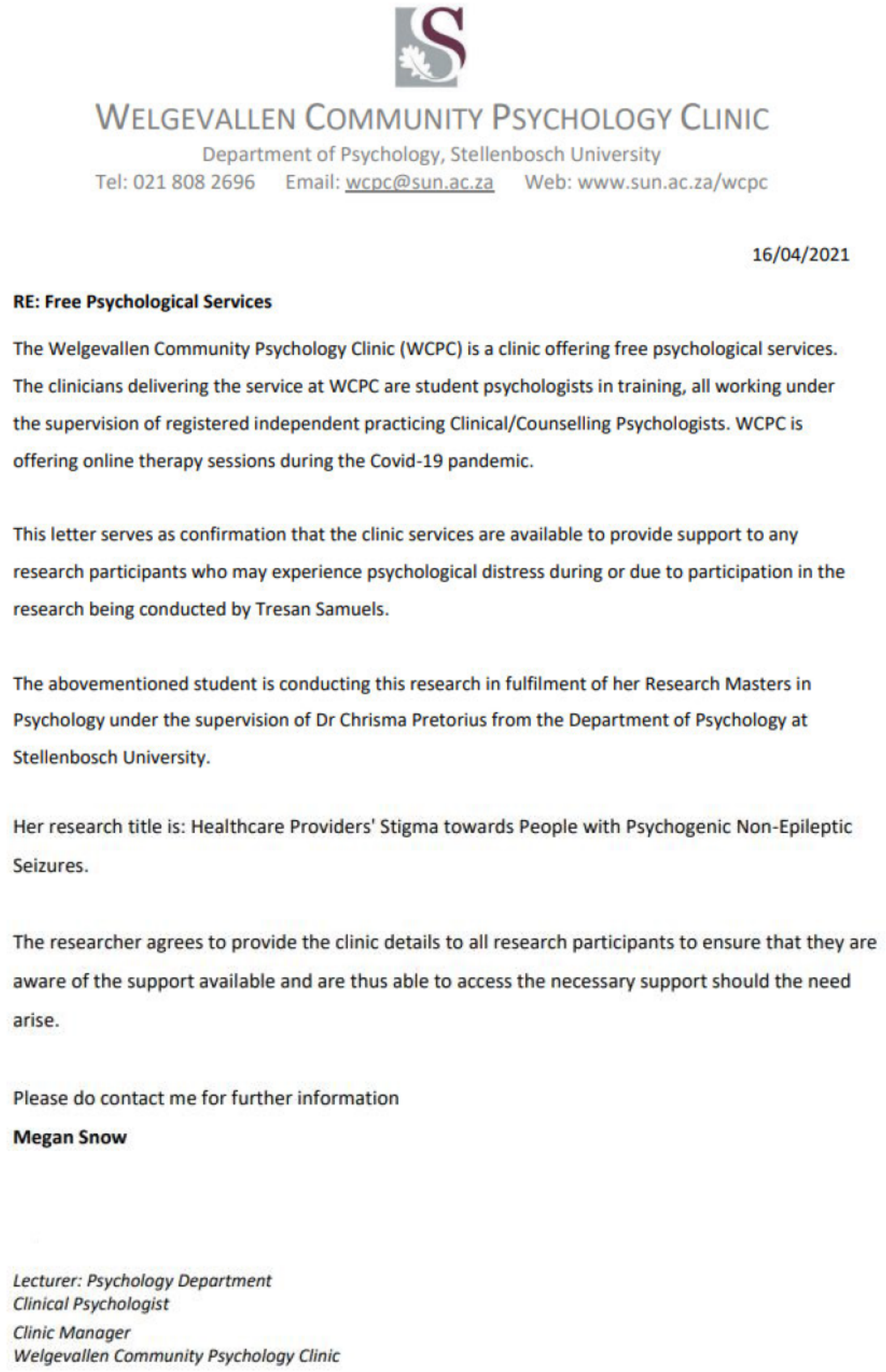
P12

My twelfth interview was with a 49-year-old male neurologist, who has been working as a healthcare provider for 25 years. This interview occurred over Microsoft Teams. We unfortunately had some technical difficulties with the sound and being able to hear what was said. Nevertheless, we still ended up with a fruitful discussion. This healthcare provider had somewhat of a serious nature to him. He made sure to clarify the questions he was unsure of to produce cautious and suitable answers, which I did appreciate. The point that he emphasised is that when making the diagnosis of PNES, one must be careful to not treat it as a diagnosis of exclusion in terms of ruling out epilepsy. I found this to be interesting as it shows how significant it is to treat PNES as its own diagnostic entity, which is contrary to the findings in some literature where healthcare providers believe that this condition should not stand on its own. He was also the first healthcare provider to suggest that the term "seizures" should not be associated with PNES, owing to there being no electrical discharge present with the condition. This resulted in me thinking about what exactly should the criteria be for seizures. Is it only a matter of electrical discharge, or should one make note of other characteristics like the movements displayed, or loss of consciousness. I think that more clarification and understanding needs to be a part of the process of formulating diagnostic terms; although, I can understand that in some cases it might be too complicated to settle on certain criteria.

P13

My final thirteenth interview was with a 58-year-old male neurologist, who has been working as a healthcare provider for 34 years. This interview was conducted over Zoom. It was a highly anticipated interview, owing to the continuous efforts that I made in order to have him be a part of my research. Even though I waited a few months and was unsuccessful with my previous attempts due to his busy schedule, I was still excited to have finally interviewed him. He was an extremely knowledgeable man who showed a sincere passion for PNES as a condition, and the outcomes of his patients' care. He provided me with information-filled long answers. He even jokingly said at the end of our interview that he could talk about PNES forever. Owing to it being potentially one of my last interviews (because I was doing my data analysis concurrently and could see that I was reaching data saturation), it was also a bitter-sweet moment to come to the realisation that this was likely to be my last interview. I thoroughly enjoyed this interview and felt that I finally had an idea of what it is like to work as a healthcare provider in terms of diagnosing and treating PNES. After this interview, I felt eager to finish analysing the data I had collected.

Appendix K: Permission for Counselling Services from Welgevallen Community Psychology Clinic



WELGEVALLEN COMMUNITY PSYCHOLOGY CLINIC
Department of Psychology, Stellenbosch University
Tel: 021 808 2696 Email: wcpc@sun.ac.za Web: www.sun.ac.za/wcpc

16/04/2021

RE: Free Psychological Services

The Welgevallen Community Psychology Clinic (WCPC) is a clinic offering free psychological services. The clinicians delivering the service at WCPC are student psychologists in training, all working under the supervision of registered independent practicing Clinical/Counselling Psychologists. WCPC is offering online therapy sessions during the Covid-19 pandemic.

This letter serves as confirmation that the clinic services are available to provide support to any research participants who may experience psychological distress during or due to participation in the research being conducted by Tresan Samuels.

The abovementioned student is conducting this research in fulfilment of her Research Masters in Psychology under the supervision of Dr Chrisma Pretorius from the Department of Psychology at Stellenbosch University.

Her research title is: Healthcare Providers' Stigma towards People with Psychogenic Non-Epileptic Seizures.

The researcher agrees to provide the clinic details to all research participants to ensure that they are aware of the support available and are thus able to access the necessary support should the need arise.

Please do contact me for further information

Megan Snow

Lecturer: Psychology Department
Clinical Psychologist

Clinic Manager
Welgevallen Community Psychology Clinic