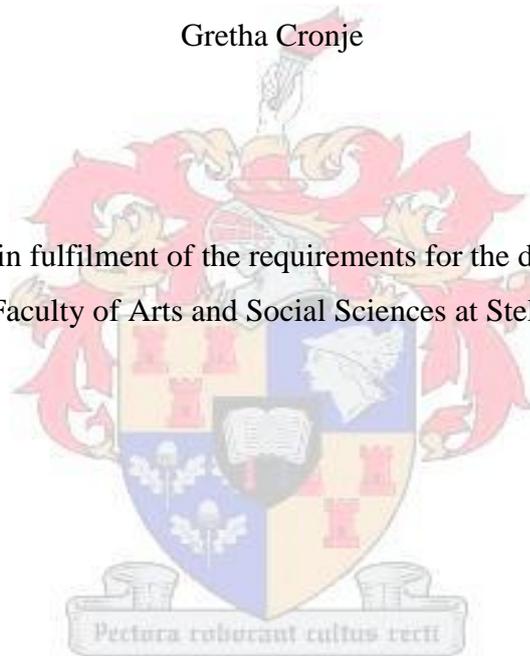


**Coping styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): A South African perspective.**

by  
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Thesis presented in fulfilment of the requirements for the degree of Master of Psychology in the Faculty of Arts and Social Sciences at Stellenbosch University



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## Declaration

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## Abstract

The primary aim of this study was to explore a possible association between the coping styles and the health-related quality of life (HRQOL) of patients with psychogenic nonepileptic seizures (PNES) in the South African context. Twenty-two PNES patients (aged 14 years or older) with confirmed video EEG were recruited from Constantiaberg Medi-Clinic and Tygerberg Hospital. These participants were matched by age and gender with a healthy control group. Participants had to complete a demographic questionnaire as well as self-reported measures of HRQOL (SF-36v2 health survey) and coping strategies (the Ways of Coping (WOC) and the Coping Strategy Indicator (CSI)). Analyses of variances were performed to explore the differences between the PNES group and the healthy control group on the various measurement instruments. The association between specific coping strategies and HRQOL was investigated by calculating Pearson's correlation coefficient. Multiple regressions were conducted to determine the extent to which HRQOL could be accounted for by each of the coping instruments. The results indicated that the HRQOL of the PNES group were significantly lower than the HRQOL of the healthy control group. The PNES participants utilised significantly more emotion-focused coping strategies, such as *escape-avoidance* and *distancing* coping strategies, in comparison to the healthy control group. The WOC and the CSI accounted respectively for 56% and 42% of the variance in the HRQOL of the sample. The results also indicated that the *escape-avoidance* coping strategies utilised by PNES participants had a significant negative effect on their HRQOL. The findings of this study provided greater insight into the coping strategies utilised by PNES participants, which have been identified as a risk factor in PNES. It also highlights that the type of coping strategies utilised by the PNES participants in our sample had a significant negative influence on their level of HRQOL. This is the first study of this nature on people with PNES in South Africa.

## Opsomming

Die primêre doel van hierdie studie was om te bepaal of daar 'n verband tussen spesifieke hanteringstyle en die gesondheidssverwante kwaliteit van lewe van pasiënte met psigogeniese nie-epileptiese aanvalle (PNEA) in die Suid-Afrikaanse konteks is. Twee-en-twintig PNEA-pasiënte (14 jaar of ouer) met 'n bevestigde video-EEG-diagnose was gewerf uit die Constantiaberg Medi-Kliniek en die Tygerberg Hospitaal. Hulle is ten opsigte van ouderdom en geslag gepaar met 'n gesonde kontrolegroep. Deelnemers moes 'n demografiese vraelys voltooi asook vraelyste wat die gesondheidssverwante lewenskwaliteit (die SF-36v2 gesondheidsvraelys) en hanteringstyle (die hanteringsmeganisme-vraelys (WOC) en die hanteringstrategie-aanduider (CSI)) meet. Analises van variansies is uitgevoer om die moontlike verskille tussen die PNEA-groep en die gesonde kontrolegroep op die verskeie metingsinstrumente te ondersoek. Die verwantskap tussen spesifieke hanteringsmeganismes en gesondheidssverwante lewenskwaliteit is ondersoek deur Pearson se korrelasie-koëffisiënt te bereken. Verskeie regressiewe analises is uitgevoer om te bepaal tot watter mate hanteringsmeganismes gesondheidssverwante lewenskwaliteit kan beïnvloed. Die resultate het aangedui dat die gesondheidssverwante lewenskwaliteit van die PNEA-groep beduidend laer was as dié van die gesonde kontrole groep. Die PNEA-deelnemers het beduidend meer gebruik gemaak van emosie-gefokusde hanteringsmeganismes, soos die *ontvlugting-vermyding* en *distansiëring* hanteringsmeganismes, as die gesonde kontrolegroep. Die WOC en die CSI het bygedra tot onderskeidelik 56% en 42% van die variansie in die totale gesondheidssverwante lewenskwaliteit-telling van die steekproef. Die resultate het ook aangedui dat die *ontvlugting-vermyding* hanteringsmeganisme wat deur PNEA-deelnemers gebruik word 'n beduidende negatiewe invloed op hul lewenskwaliteit gehad het. Die bevindings van die studie bied meer insig oor die hanteringsmeganismes wat die PNEA-deelnemers gebruik het, wat al voorheen as 'n risikofaktor vir die ontwikkeling van PNEA geïdentifiseer is. Dit lig ook uit dat die tipe hanteringsmeganismes wat die PNEA-deelnemers gebruik het, hul gesondheidssverwante lewenskwaliteit negatief beïnvloed het. Dit is die eerste studie van dié aard van persone met PNES in Suid Afrika.

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## Chapter 1 Introduction

### 1.1 Introduction

Psychogenic nonepileptic seizures (PNES) are episodes that resemble epileptic seizures (ES), but are not associated with abnormal electric discharges in the brain. These episodes are caused by an underlying psychic conflict or psychological problems (Griffith & Szaflarski, 2010; Hustvedt, 2010; Sadock & Sadock, 2007) and are considered to be beyond patients' voluntary control (Reuber, 2008). Alsaadi and Marquez (2005) define PNES as a "physical manifestation of psychological distress" (p. 849). In the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), PNES is classified as a somatoform disorder under the Diagnostic Criteria of Conversion Disorder (CD) with seizures or convulsion (American Psychiatric Association, 2000).

PNES is not a well-known disorder to the general public because the proportion of individuals diagnosed with the disorder is relatively low. The prevalence rate of CD in general population samples varies from 11/100,000 to 500/100,000 (American Psychiatric Association, 2000). The prevalence rate of PNES in the general population is unknown, but given that it is a specific subtype of CD, one would expect the rate to be lower than that of CD (Benbadis & Hauser, 2000). The most frequently used estimate of the prevalence of PNES in the US and Western Europe is between 2 to 33 per 100,000 (Benbadis & Hauser, 2000; Griffith & Szaflarski, 2010). The relatively low prevalence rate may be due to the controversy regarding the disorder itself as well as the diagnostic pitfalls of PNES (Stone et al., 2011; Trimble, 1986).

PNES patients are frequently misdiagnosed with epilepsy, as PNES resembles ES. Therefore, most PNES patients seem to be found in tertiary epilepsy centres, because of their resistance to anti-epileptic drugs (AEDs) (Bodde et al., 2009). Data from patients referred to epilepsy centres suggest an incidence rate of 20% to 30% of PNES (Reuber, 2008; Witgert, Wheless, & Breier, 2005). The incidence and prevalence rate of PNES in South Africa is still unknown because no official research on PNES has been conducted in South Africa. However, several patients are diagnosed per month with PNES at the Epilepsy Unit at the Constantiaberg Medi-Clinic in South Africa (J. Butler, Personal communication, 9 March 2011).

PNES patients are a very heterogeneous group and do not have a single psychological aetiology (Bodde et al., 2009; Lezak, Howieson, & Loring, 2004; Quinn, Schofield, & Middleton, 2010). Predisposing factors such as a history of trauma (Bowman, 2010), physical

or sexual abuse in childhood (Bakvis et al., 2009; Fiszman, Alves-Leon, Nunes, D'Andrea, & Figueria, 2004) may be associated with PNES. It has been argued that PNES is the result of dysfunctional family structures and conflict in the family (Krawetz et al., 2001). PNES is not associated with a single personality profile (Mazza et al., 2009), but these patients tend to have a more neurotic (Cragar, Berry, Schmitt, & Fakhaury, 2005), anxious (Dodrill, 2010; Owczarek, 2003) and hostile (Mökleby et al., 2002) personality profile.

Research indicates that certain coping strategies may also contribute to the development of PNES. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 110). According Lazarus and Folkman's (1984, 1987) transactional theory on emotion and coping, an individual will implement either problem-focused or emotion-focused coping strategies during a stressful event. Patients with PNES tend to use more emotion-focused coping, more specifically coping styles such as distancing and escape-avoidance (Frances, Baker, & Appleton, 1999; Lancman, Brotherton, Asconapé, & Penry, 1993). When they perceive a threat, they will deny or avoid it rather than confront it (Marquez et al., 2004; Stone, Binzer, & Sharpe, 2004; Zaroff, Myers, Barr, Luciano, & Devinsky, 2004). These coping strategies may offer a secondary gain (e.g. avoidance of a situation or not dealing with social difficulties) to the person with PNES. However, the recurrent use of escape-avoidant or distancing coping is likely to lead to a failure to seek psychological help to deal with the underlying conflict or stressful events adequately (Caplan & Plioplys, 2010).

The heterogeneity of the PNES group and the various predisposing factors of the disorder present a challenge to the treatment of PNES patients (LaFrance & Bjørnes, 2010). There is a lack of controlled trials and power studies that determine the effectiveness of the treatment of patients diagnosed with PNES (Bodde et al., 2007; LaFrance, 2008). The most common treatment plans include psychodynamic-orientated psychotherapy (Mayor, Howlett, Grünwald, & Reuber, 2010), cognitive-behavioural therapy (Goldstein, Chalder, et al., 2010; LaFrance & Bjørnes, 2010) and group psycho-education (Zaroff et al., 2004). A multidisciplinary approach that also takes the coping styles of the person into account might be the best approach to treat these individuals (Kuyk, Siffels, Bakvis, & Swinkels, 2008; Mökleby et al., 2002; Quinn et al., 2010). Studies focusing on the treatment of PNES indicate that the Health-related quality of life (HRQOL) of PNES patients should also be measured and not only the reduction of seizures when determining the effectiveness of treatment

(Bodde et al., 2009; Mercer, Martin, & Reuber, 2010; Reuber, Mitchell, Howlett & Elger, 2005).

HRQOL is the most commonly used generic framework to assess the effect of illness on an individual (Ashing-Giwa, 2005; Taylor, 2006). This multidimensional construct assesses the effect of the illness/disorder on all aspects of an individual's well-being such as the physical, functional, psychological, social, spiritual and sexual aspects ("Quality of life", 2011). It is important to measure HRQOL to determine the prevention, progress and treatment of a psychiatric disorder (Ozenli, Ozisk, Tugal & Yoldascan, 2008). PNES patients report more long-term health problems and experience their lives as more disabling than people with chronic epilepsy (Al Marzooqi, Baker, Reilly, & Salmon, 2004). Research indicates that HRQOL is significantly lower in PNES patients when compared to ES patients and healthy control groups (Al Marzooqi et al., 2004; Alsaadi & Marquez, 2005). Therefore, there seems to be a need for research on the quality of life in PNES patients utilising generic HRQOL measures (Birbeck & Vickrey, 2003; LaFrance, 2008).

## **1.2 Rationale for the present study**

Research on chronic illnesses such as diabetes mellitus and epilepsy has shown that avoidance coping styles correlate with low HRQOL (Coelho, Amorim, & Prata, 2003; Pretorius, Walker, & Esterhuyse, 2010; Westerhuis, Zijlmans, Fischer, van Anandel, & Leijten, 2011). Research also indicated that constructive coping strategies (De Ridder, Geenen, Kuijer, & Van Middendorp, 2008; Taylor, 2006) seem to improve HRQOL of patients with a chronic disease. Studies further suggest that avoidance coping is a prominent coping strategy for PNES patients (Mercer et al., 2010). Moreover, research has shown that PNES patients' scores on the HRQOL measure are significantly lower than those of epilepsy and healthy control groups (LaFrance et al., 2011). Consequently, a greater understanding of the interaction between coping and HRQOL among individuals suffering from PNES appears to be a worthwhile avenue of investigation.

Therefore, this research explored whether there is an association between coping styles and the health-related quality of life of patients with PNES in the South African context.

Hopefully, this study would form the basis of further research in the field of PNES in South Africa.

### **1.3 Aims of the present study**

The primary aim of this study was to explore a possible association relationship between the coping styles and the health-related quality of life of patients with PNES. To achieve this aim, the following research questions were formulated:

1. What is the level of HRQOL in patients with PNES compared to a healthy control group?
2. What are the differences between the kinds of coping strategies used by patients with PNES and those used by participants in the healthy control group?
3. What is the association between the specific coping strategies of patients with PNES and their HRQOL?

### **1.4 Overview of chapters**

A brief overview of PNES and the proposed study is provided in this chapter. The rationale and aims of the present study are also provided.

Chapter 2 begins with a closer look at PNES by focusing on its history, epidemiology, symptomatology and aetiology. It provides a review of the various diagnostic techniques and treatments that are used and elaborates on the prognosis of PNES and the medical burden that is associated with it. The chapter also focuses on the conceptual components of HRQOL and provides an overview of the available literature pertaining to HRQOL and PNES. The concept of coping is defined, and a brief history of coping and various coping strategies are provided. Finally, the available literature relating to PNES, HRQOL and coping is reviewed. Lazarus and Folkman's (1984) transactional theory on emotion and coping is then used to explore the understanding of how certain coping styles may lead to the development of PNES and have a negative influence on HRQOL.

Chapter 3 describes the methodology used in this study. First, the research objective, research questions and research design are stated. The chapter then focuses on the sample size, selection criteria for the two groups (the PNES group and the healthy control group) and the recruitment process that was followed. The measuring instruments that were used in the study are discussed. At the end of the chapter, the statistical procedures used to analyse the data, as well as the ethical considerations, are discussed.

Chapter 4 includes the findings of the study. The chapter begins with a presentation of the demographic results. Then the descriptive statistics of the instruments that measured HRQOL and coping strategies are discussed. Next, I focus on the differences between the PNES group

and the healthy control group on the various measurement instruments. The correlations between the components of each model (HRQOL and coping) are discussed. Finally, the multiple regressions conducted to determine the percentage of variance in HRQOL accounted for by each of the coping instruments are presented.

In chapter 5, the results of the present study are discussed and explained by incorporating information from existing literature as well as Lazarus and Folkman's (1984) transactional theory on emotion and coping in the findings. Next, the significance and the limitations of the present study are discussed. Finally, the implications for future research are discussed.

## Chapter 2 Literature review

### 2.1 Introduction

PNES is one of the most common differential diagnoses of epilepsy (Brown, Syed, Benbadis, LaFrance, & Reuber, 2011). Epilepsy is "an episodic disturbance of behaviour or perception arising from hyperexcitability and hypersynchronous discharge of nerve cells in the brain" (Lezak et al., 2004, p. 319). On the other hand, PNES is described as paroxysmal behaviour patterns that mimic epileptic seizures (ES) but are not associated with abnormal electrical discharges in the brain (Bodde et al., 2009; Kuyk et al., 2008). According to Lezak et al. (2004), PNES can mimic any type of ES. These episodes are seen as "a response to psychological or social distress, which occurs when alternative coping mechanisms are inadequate or have been exhausted" (Plug, Sharrack, & Reuber, 2009, p. 994). It is also believed that PNES arises from an unconscious process and that the patients do not deliberately fake the seizures (Goldstein & Mellers, 2006). For this reason, it cannot be regarded as malingering (Gross, 1983; Hustvedt, 2010).

### 2.2 History

Physicians as far back as Hippocrates and Aretaus differentiated between hysterical seizures and epilepsy (Reuber & Elger, 2003). Both of them emphasized the movement of the abdomen, especially the uterus, as it was believed that hysteria was a disease found exclusively in women. Although the uterine theory remained popular after the Middle Ages, a shift of emphasis occurred. Thomas Willis (1621-1675) was one of the first neurologists that highlighted the importance of the brain and emotions as the origin of hysteria. He also reported observing men with hysteria (Griffith & Szaflarski, 2010).

The association between hysteria and epilepsy continued throughout the eighteenth and nineteenth centuries. Charcot (1825-1893), a French neurologist, separated epilepsy from nonepileptic seizures by introducing the term *hystero-epilepsy* for hysteria. According to him hystero-epilepsy was the result of an abnormal nervous system. Therefore, it was regarded as a neurological condition that could be treated in the same way as any other. Pierre Janet (1859-1947), a philosopher and a researcher of the French school, was the first to coin the term *dissociation*. He applied the concept of dissociation in his explanations of hysteria. According to him, hysteria was the result of an idea (mental behaviour) that was split off from the consciousness under severe stressful conditions and functioned outside the individual's awareness and voluntary control. The Viennese neurologist, Sigmund Freud

(1856-1939), initially followed Janet's dissociative trauma hypotheses. However, he was of the opinion that an attack of hysteria was caused by the memory of childhood sexual trauma. Freud was the first to use the term *conversion* in a way that it refers to an unconscious conflict (e.g. sexual conflicts) transforming into a physical convulsion (somatic symptom), which is characteristic of PNES (Griffith & Szaflarski, 2010; Hustvedt, 2010; Kozłowska, 2005; Trimble, 1986).

The idea that hysteria was related only to sexual trauma changed during the First World War when classical hysteria was noted in soldiers (commonly referred to as "shell shock"). By the end of the Second World War, the recognition of the psychological nature of hysteria led to the introduction of psychological interventions. Throughout history, the causes of PNES shifted from the uterus, to the brain and then to the mind (Griffith & Szaflarski, 2010; Hustvedt, 2010).

It was widely accepted that PNES was not caused by organic factors (Oczarek, 2003). The introduction of new diagnostic techniques such as the simultaneous video-EEG (VEEG) in the late twenty century enabled physicians to rule out cardiac or neurological causes of seizure-like events (Hamilton, Martin, Stone, & Worley, 2010). This led to the realisation that many PNES patients were misdiagnosed with epilepsy (Griffith & Szaflarski, 2010). Currently PNES is the most common nonepileptic condition diagnosed in epilepsy (VEEG) monitoring units (Brown et al., 2011). Although new investigatory techniques make it possible to distinguish between epileptic and nonepileptic seizures, debates about the causes of PNES are still relevant today, revealing a lack of knowledge about this fascinating disorder (Griffith & Szaflarski, 2010).

From the discussion above, it is evident that the terminology of PNES has changed over the years. In the literature, terms like hysteria, hystero-epilepsy, nonepileptic seizures, nonepileptic attack disorder, pseudoseizures, hysterical pseudoseizures, pseudo-epileptic seizures and hystero-epileptic psychogenic seizures have been used to describe PNES (Bodde et al., 2009; Lezak et al., 2004; Trimble, 2010). For the purpose of this study, the term *psychogenic nonepileptic seizures (PNES)* will be used, as it is a less derogatory label than previous terms and is "currently the most appropriate term for this condition" (Griffith & Szaflarski, 2010, p. 3).

## **2.3 Classification**

Continuing debates regarding the classification of PNES exist (Goldstein & Mellers, 2006; Griffith & Szaflarski, 2010; LaFrance & Zimmerman, 2010; Stone et al., 2011). In the DSM-IV-TR, PNES is classified as a somatoform disorder under the Diagnostic Criteria of Conversion Disorder (CD) with seizures or convulsion (American Psychiatric Association, 2000). In contrast, the International Classification of Diseases (ICD-10) classifies PNES under the category of dissociative disorders with convulsions (World Health Organization, 1993). According to research, the main reason for this conflict between the two psychiatric classification systems is that the primary underlying aetiology (somatisation or dissociation) of PNES still remains unresolved (Griffith & Szaflarski, 2010; LaFrance & Zimmerman, 2010). However, both the DSM-IV and the ICD-10 agree that psychological stress factors are related to PNES and should be investigated (Bakvis et al., 2009). The DSM-IV classification of PNES is used most often in the current research (Griffith & Szaflarski, 2010; LaFrance & Zimmerman, 2010).

## **2.4 Epidemiology**

### **2.4.1 Incidence and Prevalence**

Published population-based data for PNES are limited (Duncan, Razvi, & Mulhern, 2011; Griffith & Szaflarski, 2010). I could find only three epidemiological studies reporting on the incidence of PNES to date. The first study was conducted in Iceland in the mid-1990s. It reported an incidence rate of 1.4/100,000 per year (Sigurdardottir & Olafsson, 1998). Szaflarski, Ficker, Cahill, and Privitera (2000) found an incidence rate of 3.03/100,000 per year in their study, which was performed in Hamilton County, Ohio. Their result is more than twice higher than that reported by Sigurdardottir and Olafsson (1998). The third study was performed in Scotland in the mid-2000s. It reported an incidence of 4.9/100,000 per year (Duncan et al., 2011), which is even higher than that of the previous two studies.

A good estimate of the prevalence of PNES in the general population is lacking. A possible reason for this could be the reliance on VEEG for a confirmed diagnosis of PNES, which is sometimes difficult to obtain and costly (Griffith & Szaflarski, 2010). The prevalence rate of PNES in the US and Western Europe is estimated to be between 2 to 33 per 100,000 (Benbadis & Hauser, 2000). The estimated overall incidence of PNES in the United States is 300,000 to 400,000 individuals (Martin, Gilliam, Kilgore, Faught, & Kuzniecky, 1998).

The prevalence rate of PNES in Turkey, India and Puerto Rico seems to be much higher than in the general population of the US. Research conducted in Turkey found a lifetime prevalence of 3.7% for PNES (Deveci et al., 2007). Other studies in Puerto Rico, India and Turkey indicate a gross lifetime estimate of PNES-type manifestations of approximately 3% to 4% (Martínez-Taboas, Lewis-Fernández, Sar, & Agarwal, 2010). The main reason for the difference in the prevalence between Western and Eastern Countries seems to be cultural differences (Deveci et al., 2007).

Data from epilepsy centres report a much higher prevalence rate of PNES (Woollacott, Scott, Fish, Smith & Walker, 2010), because of the general misdiagnosis of ES and PNES patients' resistance to anti-epileptic drugs (AEDs) (Bodde et al., 2009). PNES is typically diagnosed at epilepsy-monitoring units and is the most common differential diagnosis of epilepsy (Brown et al., 2011). Research indicates that 20% to 30% of patients referred to epilepsy centres for examination of seizure disorders have PNES (Benbadis & Hauser, 2000; Griffith & Szaflarski, 2010; Martin et al., 1998; Witgert et al., 2005). The incidence and prevalence rates of PNES in South Africa are still unknown, because no epidemiological studies on this condition have been conducted in South Africa. However, according to a neurologist at the Epilepsy Unit of the Constantiaberg Medi-Clinic in South Africa, several patients per month are diagnosed with PNES at their facilities (J. Butler, Personal communication, 9 March 2011).

Given the low prevalence rate of PNES, the sample size of studies focussing on PNES is generally relatively small. In their review of PNES studies, Bodde et al. (2009) found that most sample sizes consisted of 20 to 30 PNES patients. According to these researchers, the studies with bigger sample sizes were usually retrospective studies on patient files. To elaborate on the review conducted by Bodde et al. (2009), refer to Table 1 below for a summary of the sample sizes of some of the studies included in the literature review of this thesis.

Table 1

*Examples of Sample sizes of Studies focusing on PNES*

Reference	Study focus	Study design	<i>N</i> PNES <i>N</i> Control
Abubakr, A., Kablinger, A., & Caldito, G. (2003).	Clinical features and psychological analysis.	Open cohort study	23 PNES
Bakvis, P., Roelofs, K., Kuyk, J., Edelbroek, P.M., Swinkels, W.A.M., & Spinhoven, P. (2009).	Trauma, stress, and preconscious threat processing.	Open non-randomized comparative design	19 PNES 20 Healthy
Bakvis, P., Spinhoven, P., Zitman, F.G., & Roelofs, K. (2011).	Automatic avoidance tendencies	Open non-randomized comparative design	12 PNES 20 Healthy
Bewley, J., Murphy, P.N., Mallows, & J. & Baker, G.A. (2005).	Alexithymia	Open non-randomized comparative design	21 PNES 21 ES 21 Healthy
Binzer, M., Stone, J., & Sharpe, M. (2004).	Aetiology	Open non-randomized comparative design	20 PNES 20 ES
Farais, S. T., Thieman, C., & Alsaadi, T.M. (2003).	Event frequency after presentation of the diagnosis.	Open non-randomized comparative design	22 PNES 10 ES
Goldstein, L.H. & Mellers, J.D.C. (2006).	Ictal symptoms of anxiety, avoidance behaviour and dissociation.	Open non-randomized comparative design	25 PNES 19 ES
Goldstein, L.H., Drew, C., Mellers, J., Mitchell-O'Malley, & Oakley, D.A. (2000).	Dissociation, hypnotisability, coping styles and health locus of control.	Open non-randomized comparative design	20 PNES 20 Healthy
Hingray, C. Maillard, L., Hubsch, C., Vignal, J.P., Bourgognon, F., Laprevote, V., Lerond, J., Vespignani, H., & Schwan, R. (2011).	Trauma history	Open non-randomized explorative study	25 PNES
Martin, R.C., Gilliam, F.G., Kilgore, M., Faught, E., & Kuzniecky, R. (1998).	Health care resource utilization	Open non-randomized explorative study	20 PNES
Mökleby, K., Blomhoff, S., Malt, U.F., Dahlström, A., Tauböll, E., & Gjerstad, L. (2002).	Psychiatric comorbidity and hostility	Open non-randomized comparative design	23 PNES 23 Somatoform disorder 23 Healthy

Table 1 *Continued*

Reference	Study focus	Study design	<i>N</i> PNES <i>N</i> Control
Preuter, C., Schultz-Venrath, U., & Rimpau, W. (2002).	Dissociative and associated psychopathological symptoms	Open non-randomized comparative study	19 PNES 20 ES 21 ES and PNES
Prigatano, G.P., & Kirlin, K.A. (2009).	Self-appraisal and cognitive and affective functioning.	Open non-randomized comparative study	23 PNES 22 ES
Rosenberg, H.J., Rosenberg, S.D., Williamson, P.D., & Wolford II, G.L. (2000).	Trauma and posttraumatic stress disorder.	Open non-randomized comparative study	8 PNES 27 ES
Stone, J., Binzer, M., & Sharpe, M. (2004).	Illness beliefs and locus of control.	Open non-randomized comparative study	20 PNES 20 ES
Tojek, T.M., Lumley, M., Barkley, G., Mahr, G., & Thomas, A. (2000).	Stress and other psychosocial characteristics	Open non-randomized comparative study	25 PNES 33 ES
Turner, K. Piazzini, A., Chiesa, V., Barbieri, V., Vignoli, A., Gardella, E., Tisi, G., Scarone, S., Canevini, M.P., & Gambini, O. (2011).	Video-EEG, clinical and neuropsychological evaluation.	Open non-randomized comparative study	22 PNES 21 ES 10 ES associated with PNES

#### 2.4.2 Culture

It has been argued that the main reason for the difference in the prevalence rate of PNES between Western and Eastern countries may be the cultural differences between these countries (Deveci et al., 2007). According to Swartz (2006), there are "various ways in which the body is used and understood by people from different social groups" (p. 41). PNES can be seen as the bodily expression of distress in a specific social group (Martínez-Taboas et al., 2010). Although data on the cultural aspects of PNES are limited, some culturally sensitive research has been conducted on conversion and somatoform disorders, which includes PNES (Martínez-Taboas et al., 2010).

The prevalence rate of CD and the way it presents differ in various cultures (American Psychiatric Association, 2000) because in some societies, it is preferable to deal with stress

by repressing it and in others not (Deveci et al., 2007; Tseng, 2007). The most common symptoms of CD in the Asian countries may be very different from those in Western countries. For example, fainting is the most common conversion symptom in Turkey, but it is rarely seen in Western countries (Deveci et al., 2007). Tseng (2007) is of the opinion that cultural factors may play an even more prominent role in CD and dissociative disorders than other forms of psychopathology. However, research supporting this speculation is still lacking. Because it is evident that PNES is a form of CD and dissociative disorders, cultural factors are also likely to influence the frequency and form of PNES (Brown et al., 2011; Martínez-Taboas et al., 2010; Tseng, 2007).

Various sociocultural factors such as gender-specific inequalities (Bora et al., 2011; Deveci et al., 2007), education (Bora et al., 2011; Dhanaraj, Rangaraj, Arulmozhi, & Vengatesan, 2005), socioeconomic status (Deveci et al., 2007), family conflict (Dhanaraj et al., 2005) and abuse (Martínez-Taboas et al., 2010) may play a role in the development of PNES. Research conducted in Western countries (US and Western Europe) has found that sexual or physical abuse (Bowman, 2010), trauma (Hingray et al., 2011; Rosenberg, Rosenberg, Williamson, & Wolford, 2000) and conflict in the family (LaFrance, 2008; Reuber, Howlett, Khan, & Grunewald, 2007) are associated strongly with PNES.

Research conducted in Turkey indicated that most PNES patients in the studies were poorly educated married women who lived as squatters or in rural areas (Bora et al., 2011; Deveci et al., 2007). In the rural areas of Turkey, women are still in a disadvantageous position because of early termination of education, arranged marriages and gender oppression due to religious beliefs (Martínez-Taboas et al., 2010). According to researchers, PNES may be used as a defence mechanism by people who are confronted with these sociocultural factors and who live in lower socioeconomic conditions. It can also be regarded as a way of taking control in family crises where verbal communication about the problem is not allowed (Martínez-Taboas et al., 2010).

Dhanaraj et al. (2005) reported that, among married women in India, marital conflict because of a husband's infidelity and family conflict are the major precipitant factors for PNES. Among young, unmarried women, conflict with the family and the resistance of society against college education were common in their study. Conflict between married women and their mothers-in-law has also been reported as a form of stress for Indian women (Martínez-Taboas et al., 2010). These sociocultural risk factors are a result of the joint family system

that is still highly prevalent in India. The joint family system entails that women must live with their parents and siblings until they are married. Once they are married, they need to live with their husband, in-laws and other relatives and children. From the discussion above, it is clear that culture can shape the way in which PNES plays a communicative role in response to family conflict or in dysfunctional family structures.

In contrast to studies from the United States and Western Europe, sexual abuse was not found to be a precipitating factor for PNES in studies conducted in India and China (An, Wu, Yan, Mu, & Zhou, 2010; Dhanaraj et al., 2005; Martínez-Taboas et al., 2010). In a study conducted in China (An et al., 2010), only two out of the 64 PNES patients reported a history of physical abuse. According to An et al. (2010), these differences may be attributed to cultural differences between Eastern and Western countries.

From the previous literature, it seems as if sociocultural factors such as socio-economic status, dysfunctional family structures and gender inequalities play the greatest role in the development of PNES in Eastern countries. In the Western countries, however, it seems as if sexual and/or physical abuse, trauma and conflict in the family may play a role in the development of PNES. However, research that focuses more specifically on these cultural differences is still needed.

### **2.4.3 Gender**

Early history suggests that PNES is gender related and found exclusively in women (Trimble, 2010). Most of the available research shows that PNES is still more commonly (e.g. 80%) observed in women (Bora et al., 2011; Deveci et al., 2007; Hill & Gale, 2011; Holmes et al., 2001; Perrin, Sahoo, & Goodkin, 2010; Prigatano & Kirlin, 2009; Reuber, Pukrop, Mitchell, Bauer, & Elger, 2003; Szaflarski et al., 2000; Uliaszek, Prensky, & Baslet, 2012). The exact nature of the close relationship between females and PNES is not yet well understood (Schmitz, 2010).

However, two recent studies showed a higher prevalence rate of PNES in males compared to previous studies. A study conducted in the south-western part of China found that half of the patients with PNES (50%) were male (An et al., 2010). O'Sullivan et al. (2007) reported that in their 5-year retrospective review study conducted in Ireland, the prevalence rate of males with PNES was 39%.

From the literature reviewed, it seems evident that, although PNES is found more commonly among women, the prevalence rate of PNES among men seems to increase. However, research exploring gender differences in PNES is still lacking (Schmitz, 2010). Oto, Conway, McGonigal, Russel, and Duncan (2005) did not find any significant gender differences between social and aetiological factors in their study of PNES patients. However, they did find that work-related problems were a more common risk factor in men, and sexual abuse in women.

#### **2.4.4 Age**

The occurrence of PNES appears to peak during the second and third decade of life (Devici et al., 2007; Krawetz et al., 2001; Reuber, Pukrop, Bauer et al., 2003; Strutt, Hill, Scott, Uber-Zak, & Fogel, 2011a). Studies focussing on children and adolescents with PNES indicated a mean age of 14 years (Hempel, Doss, & Adams, 2010; Williams & Grant, 2000). Rare incidences of PNES have been identified in individuals younger than 4 years (Reuber, 2008) and older than 65 years (Szaflarski et al., 2000). PNES patients typically have an older age of onset than ES patients have (Cragar et al., 2005; Farais, Thieman, & Alsaadi, 2003; Hill & Gale, 2011; Tojek, Lumley, Barkley, Mahr, & Thomas, 2000).

### **2.5 Symptomatology**

The clinical features of PNES have been studied extensively (Brown et al., 2011). Proper knowledge of PNES symptomatology is important for early screening of patients for VEEG recording and for correct interpretation of the examination (Mostacci et al., 2011). Although no single clinical feature or observation is pathogenic of PNES (Hoerth et al., 2008; Reuber & Elger, 2003), certain behaviours are associated strongly with PNES (Benbadis & LaFrance, 2010).

#### **2.5.1 Behavioural seizure manifestation**

Research indicated that the following features are clinically useful to raise the question of whether the nature of a seizure may not be epileptic, but rather psychogenic; resistance to AEDS, high frequency of seizures (e.g. daily) (Benbadis & LaFrance, 2010), ictal stuttering (Benbadis & LaFrance, 2010; Hoerth et al., 2008), pelvic thrusting (Benbadis & LaFrance, 2010; Cragar, Berry, Fakhoury, Cibula, & Schmitt 2002; Hoerth et al., 2008; Mostacci et al., 2011) and preserved consciousness (Benbadis & LaFrance, 2010; Mostacci et al., 2011).

Generally the duration of the seizure is longer in PNES than in ES (Cragar et al., 2002; Reuber & Elger, 2003). The duration of PNES often exceeds 3-4 minutes, whereas a typical epileptic seizure is usually less than 2 minutes (Hill & Gale, 2011; Mostacci et al., 2011). Burneo et al. (2003) reported that the bringing of an age-inappropriate toy animal (e.g. dogs, teddy bears) to the epilepsy-monitoring unit (teddy bear sign) is associated strongly with PNES. According to them, a combination of factors, including psychiatric factors, may be the explanation behind the teddy bear sign.

Video recorded ictal eye closure (i.e. closing of the eyes during a seizure) as a semiologic feature has been studied extensively (Benbadis & LaFrance, 2010; Chung, Gerber, & Kirlin, 2006; Cragar et al., 2002; Hoerth et al., 2008). During an ES, the eyes of the patient are rarely closed, whereas it usually occurs during a PNES (Cragar et al., 2002). Most research indicates that, although ictal eye closure during the episode is relatively specific (92%) for PNES identification, it is only moderately sensitive (64%) (Brown et al., 2011; Syed et al., 2008, 2011). Unreliable observer reports of eye closure were reported to be the main reason for the low sensitivity rate of predicting PNES prior to VEEG monitoring (Syed et al., 2008).

### **2.5.2 Subjective seizure manifestation**

Previous research focused more on the visible manifestation of PNES than on the patient's subjective experience of PNES. Therefore, our understanding of the clinical significance of the various inter- individual experiences remains limited (Reuber, 2008). Plug et al. (2009) studied seizure metaphors used by patients with epilepsy and PNES to enhance understanding of the manifestation of subjective seizure. They found that PNES patients describe their seizures as a state or place they go through, whereas epileptic patients describe their seizures as more external. This means that PNES patients see themselves as the acting subject that goes into a state or place (i.e. the seizure) and then travels through it or comes out of it, whereas ES patients see the seizures as acting on them. It is important to note that, even though the PNES patient "goes into a seizure", he or she does not do so "deliberately" (p. 999).

Although a combination of the above-mentioned clinical signs may increase the likelihood of the existence of PNES for an individual patient, none can replace video EEG monitoring for diagnosis of individual episodes (Hoerth et al., 2008).

## 2.6 Aetiology

PNES patients are a very heterogeneous group and PNES do not have a single psychological aetiology (Alsaadi & Marquez, 2005; Bodde et al., 2009; Lezak et al., 2004; Quinn et al., 2010; Reuber, Howlett, Khan, & Grünewald, 2007). Differences with regard to psychosocial, psychological, and organic factors have been identified (Baslet, Roiko, & Prenskey, 2010; Lezak et al., 2004). The most common predisposing factors of PNES (e.g. trauma, family dysfunction, personality, psychiatric comorbidity, and coping mechanisms) will be discussed.

### 2.6.1 Predisposing factors

#### 2.6.1.1 *Trauma*

Research conducted mostly in Western Europe and the US has shown that exposure to trauma (Hingray et al., 2011; Rosenberg et al., 2000) and other stressful life events (such as the death of a close friend or family member or suffering from a serious illness) are associated strongly with PNES (Tojek et al., 2000). Bora et al. (2011) reported that in Turkey a traumatic life event (such as migration, divorce, sexual abuse or bereavement) was a predisposing factor in 70% of the patients. A review study focusing on research (1995-2004) on trauma and PTSD found that the reported rates of trauma and abuse (sexual and/or physical abuse) were much higher in patients with PNES than in the control groups. Trauma was reported in 44% to 100% and sexual and/or physical abuse in 23% to 77% of PNES patients (Fizman et al., 2004). Traumatic events most commonly reported are childhood sexual and/or physical abuse (Bowman, 2010), psychological trauma, severe physical illness (Turner, 2011), bereavement (Bora et al., 2011), and significant family problems (Reuber et al., 2007). It seems that a traumatic dysfunctional family environment may be the most significant predisposing factor of PNES (Bowman, 2010).

#### 2.6.1.2 *Family dysfunction*

It has been argued that PNES is the result of dysfunctional family structures and conflict in the family (Bowman, 2010; LaFrance, 2008; Reuber et al., 2007). Binzer, Stone, and Sharpe (2004) reported that PNES patients in their study recalled more rejection and less paternal warmth in childhood than patients with epilepsy.

Krawetz et al. (2001) studied the differences between ES patients and PNES patients and their families in family functioning. They found that PNES patients reported statistically

significant differences with regard to affective involvement, communication, general functioning and conflict. PNES patients experienced difficulty with affective involvement (e.g. difficulty in contacting significant relatives or overinvolvement of certain members of the family). They also struggled to communicate their feelings and needs verbally because of the perception that communication is not encouraged by members of the family or because of poor verbal communication. PNES patients also reported poorer general functioning and problems with conflict management. This indicates that PNES patients viewed their families as being more dysfunctional, particularly with regard to communication. On the other hand, family members of the PNES patients reported difficulties in defining roles. They felt that by assuming the sick role, the individual diagnosed with PNES was avoiding certain role duties in the family.

A study conducted by LaFrance et al. (2011) supports the findings of Krawitz et al. (2001). They also reported differences in affective involvement and roles between the PNES and ES group. According to Ryan et al. (quoted in LaFrance et al., 2011) affective involvement can be defined as "the extent to which the family show interest in and value for particular activities of individual family members" (p. 297), and roles "consist of the repetitive behavioural patterns families use to fulfil everyday functions" (p. 296). In the study of LaFrance et al. (2011), the general family functioning was in the unhealthy range for both the PNES and ES patients. Interestingly, they reported that the male participants' unhealthy levels of family functioning were higher than those of the female participants in both groups were. LaFrance et al. (2011) also found that greater family dysfunction in the areas of affective involvement and roles in the PNES group correlated with lower HRQOL and higher depression levels, whereas seizure frequency was unrelated to it. This may indicate that PNES patients may experience more health problems if their families are unsupportive or highly critical. Their findings demonstrate that family functioning also plays an important role in the quality of life of PNES patients.

### *2.6.1.3 Personality*

PNES is not associated with a single personality profile (Mazza et al., 2009). Inventories such as the Minnesota Multiphasic Personality Inventory (MMPI) or MMPI-2 are the most commonly used measure to analyse a personality profile specific to PNES (Griffith & Szaflarski, 2010). Previous studies indicate that PNES patients score higher on the following personality features: hypochondria (Dodrill, 2010; Mazza et al., 2009), hysteria (Dodrill,

2010; LaFrance & Bjørnaes, 2010; Lancman et al., 1993), paranoia (Mazza et al., 2009), anxiety (Hill & Gale, 2011; Owczarek, 2003), neurotic (Cragar et al., 2005; Owczarek, 2003), hostility (Cragar et al., 2005; Mökleby et al., 2002), depression (Cragar et al., 2005; Hill & Gale, 2011) and borderline personality disorder features (Binzer et al., 2004; Direk, Kulaksizoglu, Alpay, & Gurses, 2012; Hill & Gale, 2011; LaFrance & Devinsky, 2002; Turner et al., 2011). These results highlight the heterogeneity of personality profiles among PNES patients.

#### *2.6.1.4 Psychiatric comorbidity*

Generally, PNES patients have comorbid psychiatric conditions (Cragar et al., 2005). Depression and anxiety are the most commonly reported psychiatric disorders in PNES patients (Abubakr, Kablinger, & Caldito, 2003; Asmussen, Kirilin, Gale, & Chung, 2009; Goldstein & Mellers, 2006; LaFrance & Syc, 2009; Mercer et al., 2010; Mökleby et al., 2002). Other comorbid psychiatric conditions include; dissociative disorders (Goldstein, Drew, Mellers, Mitchell-O'Malley, & Oakley, 2000; Goldstein & Mellers, 2006; Mazza et al., 2009; Preuter, Schultz-Venrath, & Rimpau, 2002), somatoform disorders (Baslet, 2011; Baslet et al., 2010; Turner et al., 2011), borderline personality disorder (LaFrance & Devinsky, 2002; Stone et al., 2004), panic disorder (Szaflarski et al., 2000; Witgert et al., 2005) and posttraumatic stress disorder (Baslet, 2011; Fiszman et al., 2004; LaFrance & Devinsky, 2002; Mökleby et al., 2002).

#### *2.6.1.5 Coping mechanisms*

What characterises patients with PNES more than the presence of psychopathology is their tendency to use avoidance coping to deal with problems they encounter (Goldstein et al., 2000; Krawitz et al., 2001; Reuber, 2008). Owczarek (2003) is of the opinion that PNES patients try to solve their problems by having a seizure because they find it difficult to cope with psychological discomfort. Bewley, Murphy, Mallows, and Baker (2005) reported that the majority (90.5%) of PNES patients have alexithymia. Individuals with alexithymia have difficulty in expressing affect verbally and often communicate psychological distress in the form of physical complaints. According to them, alexithymia can also be seen as a coping behaviour.

## 2.7 Diagnosis

Despite the increase in published knowledge about PNES, the average period between the manifestation of the first seizure and a correct diagnosis remains unacceptably long at approximately 7 years (Jones et al., 2010; LaFrance, 2008; Reuber & Elger, 2003; Reuber, Fernández, Bauer, Helmstaedter, & Elger, 2002). Diagnosing PNES is difficult (Cragar et al., 2002). Complicating the diagnosis is the fact that most PNES patients have comorbid psychiatric disorders, and in 10% to 20% of patients, ES and PNES co-exist (Frances et al., 1999; Griffith & Szaflarski, 2010; Lezak et al., 2004). PNES is often misdiagnosed as epilepsy, because physicians tend to focus only on the seizures (Bodde et al., 2007; Trimble, 1986). Misdiagnosis of PNES may lead to high rates of prolonged treatment with anti-epileptic drugs (Jones et al., 2010; Reuber, Pukrop, Mithcell et al., 2003), a delay of appropriate psychological treatment (Bodde et al., 2009; Hoerth et al., 2008) and a negative effect on occupational opportunities and social development (Bodde et al., 2007).

The primary motivation for a definite diagnosis of PNES as soon as possible is to ensure cessation of AEDs (Alsaadi & Marquez, 2005) to reduce the potentially serious side effects of AEDs (Bodde et al., 2009). Secondary motivations are to initiate appropriate mental health care (Reuber & Elger, 2003), alleviate the financial burden on the patient (LaFrance, 2008) and reduce the economic burden on the health care system (Jirsch, Ahmed, Maximova, & Gross, 2011; Szaflarski et al., 2000). Martin et al. (1998) reported that, after the diagnosis of PNES, there was a significant reduction in health care utilization by PNES patients.

Early diagnosis of PNES is important (Jones et al., 2010) because a proper diagnosis is the first step in PNES treatment (LaFrance, 2008) and the outcome is better in patients with a shorter history of PNES (Reuber & Elger, 2003). Research reports a reduction in seizure frequency after the initial diagnosis of PNES has been made (Bodde et al., 2007; Farais et al., 2003; Jirsch et al., 2011).

### 2.7.1 Diagnostic techniques

PNES is one of the most common differential diagnoses of epilepsy (Brown et al., 2011). Initially, the distinction between PNES and epilepsy was based only on "the features of the attack itself" (Trimble, 1986, p. 534). However, this diagnostic technique was never hundred percent accurate (Trimble, 1986). The development of the electroencephalogram (EEG) made it possible to do inter-ictal recordings of an individual's brain activity. The EEG was "usually thought to be the most useful finding in routine EEG to identify epilepsy" (Cragar et al.,

2002, p. 32). When a seizure occurred in the presence of a normal EEG, it was most likely PNES (Trimble, 1986). However, abnormal EEG patterns during the inter-ictal phase of seizures have been reported to be unhelpful in distinguishing PNES and ES (Benbadis & LaFrance, 2010; Trimble, 2010). According to Brown et al. (2011), the main reason for this is the "over interpretation of the EEG" (p. 86) by neurologists who are not properly trained to read the EEG results. Other reasons for the misdiagnosis are the movement artefact found in some types of seizures that may be misinterpreted for spike wave activity, the limited sample of activity recorded and the high false negative rates (Cragar et al., 2002; Trimble, 1986).

Although diagnosing PNES can be complex, there has been a great improvement in the differential diagnosis between epilepsy and PNES since the introduction of simultaneous video-EEG (VEEG) monitoring 30 years ago (Bodde et al., 2009; Reuber & Elger, 2003). The VEEG is the simultaneous recording of the clinical manifestation (video) and EEG. It allows EEG rhythms to be coupled with neurobehaviour (LaFrance, 2008). VEEG is currently seen as the golden standard for the diagnosis of PNES (Benbadis & LaFrance, 2010; Chemmanam, Radhakrishnan, Sarma, & Radhakrishnan, 2009; Noe, Grade, Stonnington, Driver-Dunckley, & Locke, 2012). Benbadis and LaFrance (2010) explain as follows:

The principle of VEEG monitoring is to record an episode and demonstrate that (1) there is no epileptiform change in the EEG during the clinical event, and (2) the clinical event is not consistent with seizure types that can be unaccompanied by ictal EEG changes, i.e. making sure that the recorded event is not an epileptic seizure without epileptiform EEG changes. (p. 40)

Research found that, without a VEEG, the possibility of a definite diagnosis of PNES is only 50% specific, because certain seizure types (e.g. frontal lobe seizures) may mimic PNES symptoms (LaFrance, 2008). This means that an epilepsy monitoring unit is usually necessary to distinguish epilepsy from PNES (Szaflarski et al., 2000). Therefore, PNES is typically diagnosed by physicians specializing in the treatment of seizures (Brown et al., 2011). However, VEEG monitoring is costly and not available worldwide (Cragar et al., 2002; Hoerth et al., 2008).

Alternative diagnostic techniques for PNES include social and medical history taking (Benbadis & LaFrance, 2010; Trimble, 1986), physical signs, patient characteristics, neuropsychological testing (Dodrill, 2010), description of seizures by witness and patient

(Reuber & Elger, 2003), metaphor preference (Plug et al., 2009), Single Photon Emission Computed Tomography (SPECT) and prolactin testing (Cragar et al., 2002) and specific coping styles (Mökleby et al., 2002). However, Cragar et al. (2002) indicate that VEEG is still the most accurate diagnostic technique and that the above-mentioned techniques are helpful adjuncts to confirm the diagnosis. It is unlikely that the diagnoses of PNES can be based on clinical signs and symptoms alone (Hoerth et al., 2008).

The importance of a multi-disciplinary approach during the diagnosis and management of PNES patients has been highlighted (Bora et al., 2011; Kanner, 2010; Mökleby et al., 2002). The multi-disciplinary team usually includes a neurologist, a psychiatrist, a neuropsychologist and a social worker. Bora et al. (2011) indicated that, in their study, 91% of the PNES patients were initially diagnosed only with epilepsy by a neurologist who treated them unnecessarily with AEDs. On the other hand, only 6% of the patients who were initially examined by a psychiatrist and then referred to a neurologist for a definite diagnosis did not become AED users unnecessarily. These findings also highlight the importance of continued education about PNES for both neurologists and psychiatrists, and that physicians should always consider PNES as a differential diagnosis of a seizure disorder (Reuber & Elger, 2003).

### **2.7.2 Communicating the diagnosis**

The way in which the diagnosis of PNES is communicated to the patient plays an important role in the patients' ability to cope with the disorder and in treatment motivation (Karterud, Knizek, & Nakken, 2010). According to LaFrance (2008), the first phase of treatment begins with the diagnosis. Studies indicate that the successful communication of the diagnosis results in an improvement in seizure frequency (Farais et al., 2003; Jirsch et al., 2011; Zaroff et al., 2004). A diagnosis of PNES should be communicated to the patient in a clear and respectful manner as early as possible (Bodde et al., 2007; Duncan et al., 2011).

Achieving the patients' acceptance of the diagnosis is also important (Bodde et al., 2007). Karterud et al. (2010) found that the switch in the diagnosis from epilepsy to PNES was difficult for patients to understand and accept. They experienced feelings of hopelessness and helplessness when the causes of the seizures were unclear. Another qualitative study found that patients with PNES wanted a scientific explanation and felt rejected when a psychological cause was suggested (Green, Payne, & Barnitt, 2004). When communicating the diagnosis, the neurologist/psychologist should focus on the various causes of PNES and

not only on trauma as a predisposing factor. Studies indicate that explanations that focus only on trauma as a cause of PNES make some patients feel confused and unconvinced, because many feel they have not experienced any severe trauma in their lives (Baxter et al., 2012; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). These findings highlight that a clear understanding of the disorder is necessary for patients to accept the diagnosis and to treat these patients successfully.

## **2.8 Treatment**

There is a paucity of controlled trials that determine the effectiveness of the treatment of patients diagnosed with PNES (Barry et al., 2008; Bodde et al., 2007; LaFrance, 2008; LaFrance & Devinsky, 2002; Reuber, 2008). Although PNES patients are some of the most challenging to treat in medical practice (LaFrance, 2008), research demonstrates that PNES is a treatable disorder (LaFrance & Bjørnaes, 2010). In the literature, no consensus exists about the types of treatment that may be most effective for treating PNES (Zaroff et al., 2004). It also does not seem possible to develop a "one-size fits all" treatment, because of the multifactorial aetiology of this group (Reuber, 2008). Continuous communication among the various specialists (such as psychiatrists, neuropsychologists and neurologists) is necessary to ensure that a comprehensive and effective treatment plan is implemented (Kanner, 2010).

Even though seizure cessation is important in treating PNES (Kuyk et al., 2008), research indicates that the outcome of treatment should not only be measured in terms of seizure reduction or cessation (Reuber et al., 2005; Mercer et al., 2010). Reuber et al. (2005) found that almost half of the patients remain unproductive and continue to report symptoms of psychopathology (e.g. depression and anxiety) even after they have become seizure free. A more comprehensive outcome measure that includes quality of life (Reuber et al., 2005; Testa, Schefft, Szaflarski, Yeh, & Privitera, 2007), psychosocial domains (LaFrance, 2008; Mercer et al., 2010), behavioural measures and employment status (Bodde et al., 2009) should be used to evaluate treatment outcomes.

### **2.8.1 Specific treatment**

Mostly, treatment recommendations are still based on theory (Alsaadi & Marquez, 2005) because there is not a specific model that is generally accepted that explains the psychogenic factors leading to PNES. The most common treatment plans based on the PNES aetiology include psychodynamic orientated psychotherapy, group psychotherapy, cognitive-

behavioural therapy, family therapy and a multidisciplinary approach (LaFrance & Bjørnaes, 2010; LaFrance & Devinsky, 2002).

#### *2.8.1.1 Psychodynamic therapy*

Psychodynamic therapy is the most commonly used treatment for PNES (LaFrance & Devinsky, 2002). Mayor et al. (2010) found that, more than four years after psychodynamic therapy intervention, a quarter of the patients had become seizure free and a significant seizure reduction was achieved in 40.4% of the patients. There was also a significant reduction in health care utilization. In a previous study, these researchers also indicated that psychodynamic therapy can improve emotional distress and health-related quality of life in PNES patients (Reuber et al., 2007). These results indicate that psychotherapy may be an effective treatment of PNES (Mayor et al., 2010).

#### *2.8.1.2 Group psychotherapy*

To date, only three prospective uncontrolled trials that use group psychotherapy in PNES patients have been reported (Bullock, 2010). The first group therapy study that focused on PNES was completed in 2002 by Prigatano, Stonnington, and Fischer. They conducted two separate 24 weeks group psychotherapy programs of 1.5 hours per session for PNES patients. One of their goals was to explore whether psychotherapeutic interventions reduce seizure frequency. Only 9 of the 15 patients completed most of the therapy sessions. Of those who completed most of the sessions, 66% reported a reduction in seizure frequency.

Zaroff et al. (2004) provided a 1-hour weekly group psychotherapy session to ten PNES patients for 10 weeks. Significant reductions in posttraumatic and dissociative symptoms were found, as well as a decrease in seizure frequency. A decrease in emotionally based coping mechanisms and an increase in quality of life were reported.

Barry et al. (2008) also focused on group psycho-education. Their overall goal was to develop verbal expression of emotional distress by emphasizing assertive coping strategies rather than passive avoidant behaviour. Seizure reduction and improvement in quality of life were found. Based on these studies, group therapy focusing on interpersonal issues such as coping may be an effective treatment method in some PNES patients (Bodde et al., 2009). Group therapy also seems to have some benefits over individual therapy that may be meaningful to PNES patients. Group therapy is usually less costly, it can address comorbid conditions that are commonly found in PNES effectively and it increases an individual's

social support status (Bullock, 2010). However, no formal conclusion can be derived from the results of these results as these assumptions are only based on limited data.

#### *2.8.1.3 Cognitive-behavioural therapy (CBT)*

To date, only two research groups have systematically evaluated CBT as a treatment for PNES (Goldstein, LaFrance, Chigweder, Mellers, & Chalder, 2010). Goldstein, Chalder et al. (2010) compared CBT with standard medical care (SMC) as treatment for PNES. They randomly selected 66 PNES patients who received either CBT (plus SMC) or only SMC over 4 months. At the three-month follow-up, the CBT group had more patients who had become seizure free or had a reduction in PNES frequency than the SMC group. Improvement in the social adjustment scale and health service measure was found in both groups.

LaFrance et al. (2009) conducted a prospective clinical trial, assessing the effect that CBT has on seizure frequency, psychiatric symptoms and other social variables of PNES patients. Of the 17 PNES patients that completed the twelve-weekly CBT sessions, 65% were seizure free at their final CBT session. Improvement in psychiatric symptoms (e.g. depression, anxiety and somatic symptoms), psychosocial functioning (e.g. family functioning and coping strategies) and quality of life were reported. The findings in both of the above-mentioned studies suggest that PNES patients may benefit from CBT.

#### *2.8.1.4 Family therapy*

PNES patients experience their families as dysfunctional; therefore, researchers suggest that family education and family therapy may be beneficial in treating PNES patients (Krawetz et al., 2001; LaFrance et al., 2011). However, no research could be found that used family therapy as an intervention and documented its effectiveness. Only a case report of a couple that participated in brief family therapy reported that the reciprocal relationship between family functioning and a patient's PNES symptoms can be treated with family therapy (Archambault & Ryan, 2010).

#### *2.8.1.5 Multidisciplinary interventions*

A multidisciplinary approach that combines psychological and neurological perspectives might be the best approach to treat these individuals (Bodde et al., 2009; Jones et al., 2010; LaFrance & Bjørnaes, 2010; Mökleby et al., 2002). Hypnosis may also be a valuable tool as part of a more comprehensive treatment programme (Brooks, Goodfellow, Bodde, Aldenkamp, & Baker, 2007; Moene & Kuyk, 2010). Kuyk et al. (2008) treated 26 PNES

patients for an average of 4.8 months by using a multidisciplinary approach. This treatment included a combination of family therapy, individual therapy and group therapy. The treatment was aimed at coping skills, stress management, cognitive restructuring, stimulus differentiation and trauma treatment. At the six-monthly follow-up, half the patients became seizure free, and most of the other patients reported a reduction in seizure frequency. Their scores on the anxiety, dissociation and depression measures also decreased. Their health-related quality of life increased, and their coping mechanisms improved. These outcomes suggest that multidisciplinary therapy could be an effective approach to treat PNES (Kuyk et al., 2008).

### **2.8.2 Further research**

The previous discussion highlights that there seems to be a lack of literature on the psychological treatment of PNES patients (Goldstein, LaFrance, et al., 2010). Adequately designed controlled studies are also needed to evaluate the effectiveness of available methods of treatment (Zaroff et al., 2004). According to Brown et al. (2011), one of the benchmarks for epilepsy research of the National Institute of Neurological Disorders and Stroke (NINDS) is to develop treatments for PNES, because of the incidence and prevalence of the disorder and the lack of treatment efficacy data.

## **2.9 Prognosis**

The prognosis of patients diagnosed with PNES is still unclear (Bodde et al., 2009). In general, the prognosis of patients diagnosed with PNES seems to be poor. Bodde et al. (2007) found that, 4-6 years after a diagnosis of PNES, seizure cessation occurred in about one third, seizure reduction occurred in one third and chronic seizures continued in another third of the patients. Another study found that, four years after diagnosis, a quarter of the patients had become seizure-free and that significant seizure reduction (>50%) occurred in 40.1% of the patients (Mayor et al., 2010). Similar to previous studies, Lanceman, Brotherton, Asconapé, and Penry (1993) indicated that only 25.4% of the PNES patients were seizure free after a mean follow-up of 5 years.

Jones et al. (2010) found that, in their 10-year follow-up of PNES patients, 83% of the respondents continued to have PNES seizures. They found that only 12% had a "good outcome" (seizure free and not dependent). Their findings are in line with another study, which found that only 16.2% of respondents had a "good outcome" after four years of their

diagnosis of PNES (Reuber, Pukrop, Bauer et al., 2003). In the same study, more than half of the patients were dependent on social security.

Even though limited research has been done on long-term prognosis (Reuber, 2008), studies consistently report that a third to a fourth of patients become chronic PNES sufferers (Bodde et al., 2009). However, it should be noted that information about more global measures of outcomes in patients with PNES are lacking (Jones et al., 2010).

## **2.10 Medical Burden**

Few research-funding initiatives have been directed towards understanding and treating PNES, despite the substantial financial cost related to PNES. The direct and indirect costs associated with PNES are not well-researched (Hamilton et al., 2010). The direct costs associated with PNES can be divided into four categories, namely the cost of misdiagnosis, pre-diagnosis, health care utilization and the use of AEDs. Factors such as unemployment and financial dependency are associated with the indirect cost of PNES.

The misdiagnosis of PNES is costly to society, the health care system and patients. These costs include medical costs resulting from unnecessary hospitalization, repeated treatment for what is mistakenly thought to be epilepsy, medication costs, delayed referral to appropriate psychiatric treatment and unemployment (Brown et al., 2011). In the United States, the cost of PNES-related misdiagnosis per patient has been estimated to be between \$25 000 (Martin et al., 1998) and \$100 000 per patient (Reuber & Elger, 2003) or \$100 to \$900 million per year in medical services (Brown et al., 2011). Taking into account the annual incidence of PNES in the USA and the average duration prior to diagnosis, the cost of misdiagnosis is estimated to incur \$2.5 to \$10 billion dollars (Martin et al., 1998).

In addition, the average cost of medical pre-diagnosis (e.g. outpatient visits, ER visits, diagnostic procedures, laboratory tests and medication) of PNES in the US has been estimated to range from \$8 156 (Martin et al., 1998) to \$15 000 (Binder & Salinsky, 2007). Although it is expensive to make a diagnosis of PNES, a definitive diagnosis has a long-term financial benefit (Jirsch et al., 2011).

Patients with PNES frequently use health care resources (Asmussen et al., 2009; Dworetzky et al., 2006). Mayor et al. (2010) found a significant decrease in health care utilization by PNES patients 50 months after diagnosis, resulting in an annual health care expenditure saving of at least £245 (\$408). Martin et al. (1998) indicated that, in the six-month period

prior to PNES diagnosis, their patients visited the emergency room (ER) six times on average at an estimated cost of \$3 400 per visit. ER visits were reduced by 97%, and total seizure-related medical cost was reduced by 84% in the 6 months following PNES diagnosis. Their findings support those of Jirsch et al. (2011), who found a 39% reduction in ER visits two years following the diagnosis.

The cost related to AEDs can be substantial, and is one of the most common costs incurred by patients with PNES (Hamilton et al., 2010). Most PNES patients take AED at the time of diagnosis (Binder & Salinsky, 2007; Bora et al., 2011; Prigatano, & Kirlin, 2009). In their study, Chemmanam et al. (2009) indicated that the most evident financial gain after the diagnosis of PNES was the decrease in AED expenditure.

A significant number of patients diagnosed with PNES are unemployed or dependent on financial assistance (Hamilton et al., 2010). The cost associated with lost work is estimated at \$22 000 per year per patient with PNES (Binder & Salinsky, 2007). O'Sullivan et al. (2007) found that, five years after the diagnoses of PNES patients, 47% of the individuals were still unemployed, and 26% of patients with PNES were not living independently. Martin et al. (1998) reported that, at the time of PNES onset, 69% of patients were fully employed, whereas at the time of diagnosis of PNES, only 20% were in the workforce. Other studies indicate employment rates of 24.1% (Duncan et al., 2011) and 21% (Bora et al., 2011) at the time of first presentation with PNES. Lancman et al. (1993) found that, in most cases, PNES was the reason for unemployment.

PNES patients represent a public health problem due to the diagnostic difficulty, the poor prognosis and their unemployment status (Hamilton et al., 2010). The average medical cost in the South African context is unknown, but given that these patients represent a proportion of patients seen for seizure disorders by doctors and neurologists, and taking into account that seven years is the average length before a patient is diagnosed with PNES, the burden of PNES on medical aids may be substantial. It is important to determine the direct and indirect cost associated with PNES, because these patients represent a substantial proportion of patients seen for seizure disorders by primary care physicians and neurologists (Hamilton et al., 2010).

## 2.11 HRQOL

### 2.11.1 The concept of HRQOL

The field of quality of life measurement has been evolving for more than 30 years (Lohr, 2002). Quality of life is a broad, multidimensional concept that refers to an individual's total well-being. This includes all the various aspects of an individual's life, such as the emotional, social and physical aspects (World Health Organization Quality of Life [WHOQOL] Group, 1995). *Health-Related Quality of Life (HRQOL)* is the term used in health care and medicine that refers to the effect of a disorder, a disease or a disability on the individual's well-being over time ("Quality of life", 2011). The WHOQOL group (1995) defines HRQOL as

Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. (p. 1405)

This multidimensional construct is currently assessed through the use of questionnaires ("Quality of life", 2011) and is the most commonly used generic framework to assess the effect of illness on an individual (Ashing-Giwa, 2005; Taylor, 2006). HRQOL is based on subjective and objective domains. The subjective (e.g. psychological well-being and life satisfaction) domain is based on the individual's perception of how his/her life matches some internal standard. The objective (e.g. health, income and environment) domain is more concerned with the physical functioning and living standards of the individual (Romney & Evans, 1996).

HRQOL measures are important for a number of reasons, including determining the prevention, progress and treatment of disorders (Ozenli et al., 2008), measuring the effectiveness of health care interventions (Brazier, Roberts, & Deverill, 2002; Health measurement Research Group, 2011), providing insight into the relationship between risk factors and HRQOL ("Centers for Disease Control", 2012), assessing the effect of chronic disease (Mercer et al., 2010; Sprangers et al., 2000) and the effect of treatment on the quality of life of individuals (Taylor, 2006; WHOQOL Group, 1995). HRQOL measures also allow the patient's experience to be accounted for during research (Birbeck & Vickrey, 2003) and treatment (Ware & Sherbourne, 1992). PNEs, which is the focus of this study, affects various

aspects of an individual's life and may also become chronic. Therefore, it is also important to assess the HRQOL of these patients.

### **2.11.2 HRQOL measures**

Generally, HRQOL is investigated by means of self-report questionnaires. These questionnaires can be classified into two categories, namely generic and disease-specific instruments (Mercer et al., 2010; "Quality of life", 2011). Generic instruments can be used across different disease types and capture information about the various domains of quality of life (Mercer et al., 2010). It can be used to compare different treatments directed at groups suffering from different diseases, which is not always possible with disease-specific measures (Romney & Evans, 1996; Ware & Sherbourne, 1992). On the other hand, disease-specific measures are designed for specific patient populations or diagnostic groups (e.g. asthma, cancer, epilepsy). These measures seek changes that clinicians and patients think are important for that particular disease (Mercer et al., 2010).

For example, the Adolescent Asthma Quality of Life Questionnaire has been developed specifically for individuals with asthma (Rutishauser, Sawyer, Bond, Coffey, & Bowes, 2001; Van de Ven, Engels, Sawyer, Otten, & van den Eijnden, 2007) whereas the Quality of Life in Epilepsy Inventory (QOLIE)-89, QOLIE-31 and QOLIE-10 (Devinsky et al., 1995) are disease-specific measures that have been developed for patients with epilepsy. The Short-Form Health Survey (SF-36) (Ware & Sherborne, 1992) and the WHOQOL-100 (WHOQOL Group, 1995) are examples of generic measures of quality of life. Most studies that investigate the HRQOL of PNES patients use patients with ES as the control group. The SF-36 and the QOLIE questionnaires are the most commonly used HRQOL measures in patients with PNES and ES (Mercer et al., 2010).

### **2.11.3 HRQOL in PNES**

PNES patients report long-term health problems (Al Marzooqi et al., 2004) and low HRQOL (Jones et al., 2010). Most studies that focus on HRQOL in PNES patients compare PNES patients with ES as a control group (Mercer et al., 2010). Results indicate that HRQOL is significantly lower in PNES patients than it is in patients with epilepsy (Alsaadi & Marquez, 2005; Al Marzooqi et al., 2004; Szaflarski et al., 2003a; Szaflarski et al., 2003b; Testa et al., 2007) and in the general population (Mercer et al., 2010; Ozenli et al., 2008; Uliaszek et al., 2012).

### *2.11.3.1 Factors that may influence HRQOL in PNES*

Factors that might influence the HRQOL in patients with PNES are still poorly understood. Some factors that may be associated with low HRQOL in PNES patients are seizure frequency (Lawton, Mayor, Howlett, & Reuber, 2008), adverse effects of anti-epileptic drugs (Szaflarski et al., 2003a), depression (Szaflarski & Szaflarski, 2004), mood state (Szaflarski et al., 2003a; Testa et al., 2007) and family functioning (LaFrance et al., 2011).

The relationship between HRQOL and the frequency of PNES is complex (Lawton et al., 2008). Discrepant results regarding the effect of the frequency of seizure on HRQOL are reported. Some studies reported that cessation of seizure (Kuyk et al., 2008; Quigg, Armstrong, Farace, & Fountain, 2002) or a reduction in the frequency of seizure (Lawton et al., 2008) improved the HRQOL of PNES patients while other studies indicated that it did not improve the HRQOL of other PNES patients (Reuber et al., 2005; Szaflarski et al., 2003b). Quigg et al. (2002) found that only complete cessation of PNES increased HRQOL. According to their study, the HRQOL did not improve proportionally with the reduction in seizure frequency. However, the HRQOL of patients who reported cessation of PNES was significantly higher than those with continuing PNES. Kuyk et al. (2008) reported similar results. In their study, the HRQOL increased only slightly, even though there was a reduction in the frequency of seizure. They also found that better psychological outcome was reported by patients whose PNES had ceased. Another study indicated that a reduction in seizures (rather than only a cessation of seizures) may improve HRQOL (Lawton et al., 2008). In contrast to the above-mentioned findings, Reuber et al. (2005) indicated that although reduction or remission of seizure is important, it is not the strongest predictor of HRQOL in PNES patients. In their study, almost 50% of the PNES patients whose seizures had ceased remained unproductive and continued to report symptoms of psychopathology (i.e. depression, somatoform and anxiety disorders).

In line with the findings of Reuber et al. (2005), other studies indicate that PNES frequency alone does not improve HRQOL, but other factors such as depression and side effects of medication also contribute to low HRQOL in PNES patients (LaFrance & Syc, 2009; Szaflarski et al., 2003a, 2003b). Studies that focused on the relationship between depression, HRQOL and the types of seizure (ES vs. PNES) found that depression contributes to lower HRQOL in both PNES and ES. Compared to the ES group, the PNES patients were more depressed and also reported lower HRQOL than the ES group (Szaflarski & Szaflarski, 2004;

Szaflarski et al., 2003a, 2003b). Szaflarski et al. (2003a) reported that the PNES patients in their study had more adverse side effects of AED than the ES group. They also indicated that the medication side effects influenced the HRQOL negatively in both the PNES and ES groups.

Researchers that investigated whether aspects of mood and personality could explain HRQOL differences between diagnostic groups (ES and PNES) could not find any significant correlation (Strutt, Hill, Scott, Uber-Zak, & Fogel, 2011b; Testa et al., 2007). However, Testa et al. (2007) reported that, when personality factors were not considered, current mood states were strongly related to HRQOL. However, when seizure diagnosis (ES or PNES) were taken into account, current mood state moderated the relationship between HRQOL and seizure diagnosis, meaning that PNES patients reported lower HRQOL even though they reported minimal mood disturbances.

LaFrance et al. (2011) evaluated different contributions of aspects of family functioning (FF) on health-related quality of life (HRQOL) in patients with PNES vs. ES. They reported that the mean general family functioning for both the PNES and the ES groups was in the unhealthy range, but that aspects of FF predicted HRQOL differently between the groups. Lower FF in the areas of Affective Involvement and Roles correlated with lower HRQOL and higher symptoms of depression in the PNES group. Even after controlling for depression, duration of illness and frequency of seizure, poorer FF still predicted lower HRQOL. These results suggest that FF plays a key role in the HRQOL of PNES patients.

### 2.11.3.2 *The influence of PNES on the HRQOL domains*

HRQOL measures consist of various health domains/scales. Studies that focused on the HRQOL mostly used the SF-36 (Ware & Sherborne, 1992) and the QOLIE-89 (Devinsky et al., 1995; Mercer et al., 2010) scales. The QOLIE-89 incorporates the eight health dimensions of the SF-36, but has additional subscales that specifically relate to epilepsy (e.g. medication side effects, seizure worry) as it is an epilepsy-specific instrument. The SF-36 measures the following eight health dimensions: *physical functioning*, *general health*, *bodily pain*, *vitality*, *mental health*, *social functioning*, *role limitation – physical*, and *role limitation – emotional* (Ware & Sherborne, 1992).

The *physical functioning* subscale refers to a limitation on physical activities (e.g. climbing stairs, walking moderate distances or dressing) due to actual physical disabilities. *General*

*health* refers to the individual's perception of his/her overall personal health. The *bodily pain* subscale measures the intensity of pain experienced by the individual. *Vitality* refers to the person's subjective well-being such as his/her energy levels. The *mental health* subscale measures emotional well-being. Whether the emotional problems and physical health of an individual interfere with his/her social activities is measured on the *social functioning* subscale. *Role limitation – physical* and *role limitation – emotional* respectively refers to whether a person experiences problems with his/her work or other daily activities because of his/her physical health or emotional problems (Ware & Sherbourne, 1992).

Strutt et al. (2011b) used the QOLIE-89 to compare the HRQOL between patients with PNES and ES. They found that PNES patients reported a lower HRQOL than ES, which included poor social support, an increase in pain and fatigue, role limitations due to emotional problems and a decline in general physical well-being. Another study that used the QOLIE-89 to measure HRQOL found that the lowest scores of the PNES patients were in those categories that reflect concerns about poor physical functioning and consequent physical limitation, rather than emotional "well-being" or "limitations" (Jones et al., 2010).

An earlier study also indicated that PNES patients reported significantly lower physical health across domain scales when compared with the ES group (Breier et al., 1998). These results suggest that PNES patients focus on physical rather than psychological explanations for stress. In line with this, Szaflarski and Szaflarski (2004) reported that the low HRQOL of PNES patients correlated significantly with depression and the SF-36 *role limitation – physical* subscale in their study. Their results indicate that the patients with PNES who were depressed experienced significantly more problems with daily activities (such as work) because of their physical health when compared with the ES group and the normative scores for clinical depression. On the other hand, on the *role limitation – emotional* subscale of SF-36, the low HRQOL of the PNES group did not correlate significantly with depression. This indicates that the PNES patients with depression did not report more problems at work or with other daily activities because of their emotional problems when compared with the ES group or the norms for clinical depression. These results support the statement that PNES patients tend to focus on the physical rather than the emotional aspects of HRQOL.

A study that compared the HRQOL between PNES and ES patients found that PNES had significant lower scores than the ES on most of the SF-36 domains, including *role limitation – emotional*, *mental health*, *general health*, *role limitation – physical*, *bodily pain* and *fatigue*

domains. Only on the *physical* or *social functioning* domains, no significant differences were found. PNES patients also reported more long-term health problems, suggesting that they regarded their lives as more disabling than the lives of people with ES (Al Marzooqi et al., 2004).

It seems to be a trend for PNES to report higher levels of impairment on the *role limitation – physical* scale than on the *physical functioning* scale of the HRQOL (Al Marzooqi et al., 2004; Lawton et al., 2008; Testa et al., 2007). Literature suggests three possible explanations for this: First, it could be that the *physical function* subscale score of the SF-36 does not reflect other aspects of physical dysfunctioning associated with PNES very well, as the questions are strongly based on mobility (e.g. walking a specific distance) (Lawton et al., 2008). Second, it is possible that, for PNES patients, the impairment of role functioning is not related to actual physical disability, but related more to self-imposed restrictions and the avoidance of on activity due to fear of having a seizure (Lawton et al., 2008; Mercer et al., 2010). Third, PNES patients "may in the absence of any physical pathology, exaggerate their poor health status in order to justify their level of disability" (Al Marzooqi et al., 2004, p. 74).

The above-mentioned research results indicate that PNES seems to have a negative effect on the HRQOL of these patients. Previous studies suggest that the outcome of treatment targeted at PNES patients should also focus on the improvement of HRQOL (Lawton et al., 2008; Martin et al., 1998; Mayor et al., 2010). There also seems to be a need for research on the quality of life in PNES patients utilising generic HRQOL measures (Birbeck & Vickrey, 2003; LaFrance, 2008). Therefore, this study investigates the level of HRQOL in patients with PNES utilizing a generic HRQOL measure.

## **2.12 Coping**

### **2.12.1 Concept of coping**

Extensive research studies on coping and how it affects mental health exist (Moore, & Constantine, 2005) and relate to illness (Van Rhenen, Schaufeli, van Dijk, & Blank, 2008; Somerfield & McCrae, 2000). Numerous measures have been developed to assess peoples' ways of coping, and various conceptual coping frameworks have been proposed (Skinner, Edge, Altman, & Sherwood, 2003). To date, the issue of whether coping should be addressed as a state or trait variable has received much attention (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984; Moos & Holahan; 2003).

Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 110). In their definition, coping is process orientated and has to be considered as a behaviour that is determined primarily by environmental demands. In contrast, coping can be considered as a personality trait (Carver et al., 1989; Moos & Holahan; 2003). According to these scholars, individuals use specific coping styles to deal with a stressful event. These coping styles are relatively stable and are thought to be like personality traits in that they predispose people to cope in a certain way when events become stressful (Taylor, 2006).

Nowadays, Lazarus and Folkman's (1984) conceptualization of coping behaviour is probably the most widely accepted and popular model (Van Rhenen et al., 2008). According to Lazarus (1999), an individual will implement two main coping strategies in a threatening event, namely problem-focused coping and emotion-focused coping. Problem-focused coping predominates when conditions of stress are appraised as changeable and are viewed as falling within the person's control. Emotion-focused coping are predominant when conditions are appraised as unchangeable. Each of these two main coping strategies consists of different processes to cope with a particular stressful encounter. Problem-focused coping consists of confrontive coping, self-controlling, seeking social support and planful problem solving. Emotion-focused coping consists of escape-avoidance, distancing, accepting responsibility and positive reappraisal. Refer to Table 2 for a description of each of the processes.

Table 2

*Description of Coping Strategies (Lazarus & Folkman, 1984, p. 11)*

Coping Process	Description
	<i>Problem-focused</i>
Confrontive coping	Describes aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking.
Self-controlling	Describes efforts to regulate one's feelings and actions
Seeking social support	Describes efforts to seek informational support, tangible support and emotional support.
Planful problem solving	Describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem.
	<i>Emotion-focused</i>

Distancing	Describes cognitive efforts to detach one and to minimize the significance of the situation.
Accepting responsibility	Acknowledges one's own role in the problem with a concomitant theme of trying to put things right.
Escape-avoidance	Describes deliberate problem-focused efforts to escape or avoid the problem.
Positive reappraisal	Describes efforts to create positive meaning by focusing on personal growth. It has a religious dimension.

Whether a coping process is adaptive or maladaptive depends on the modality being studied. A coping process is adaptive when it effectively improves the adaptation outcome (e.g. better physical or emotional health). Coping strategies are most effective when they are matched with the particular problem for which they are most useful (Taylor, 2006). This means that people who have multiple coping strategies may be better able to engage in this matching process than those who have a predominant coping style.

According to Lazarus (1993), no coping process is universally good or bad, but some might be better than others. Lazarus and Folkman (1987) found a relationship between psychological symptoms and coping. They found that problem-focused coping is associated with a lower increase in psychiatric symptoms. On the other hand, emotion-focused coping such as *distancing* and *escape-avoidance* are associated with symptoms of depression and anxiety. In line with this, other studies also reported that psychiatric symptoms or conditions (such as depression) tend to be associated with *escape-avoidance* coping strategies (Felsten, 1998; Moos & Holahan, 2003). According to Felsten (1998), a trend that emerged from previous research indicates that emotion-focused coping and avoidance have generally been associated with negative outcomes, whereas problem-focused coping and seeking of social support have usually been associated with positive outcomes. It seems that the coping process can be associated with the emotional outcome of stressful life events (Folkman & Lazarus, 1988a). A chronic illness may be viewed as a stressful life event because it affects all aspects of a patients' life (Taylor, 2006). According to Van der Zaag-Loonen, Grootenhuis, Last, and Derkx (2004), each chronic disease entails different types of disease-related stressors.

Research focusing on coping strategies among chronically ill patients found that the chronically ill tend to use more emotion-focused coping, such as escape-avoidant and positive reappraisal and less problem-focused coping such as problem solving and confrontive coping (Taylor, 2006). Previous research also indicates that the use of avoidant

coping is disadvantageous for psychological adjustment, associated with increased psychological distress and may aggravate the disease process itself (De Ridder et al., 2008; Taylor, 2006). If patients fail to express their emotions, it may leave these emotions unresolved, which can affect the patients' health negatively (De Ridder et al., 2008).

### **2.12.2 Coping in PNES**

According to Lazarus (1999), coping can be regarded as an individual's response to manage stressful life conditions. A life condition can be experienced as stressful / threatening when people appraise the condition as unpredictable, uncontrollable and overloaded (Lazarus & Folkman, 1987). It has been reported that PNES patients have a locus of control that is more external (e.g. they experience events as unpredictable and out of control) when compared with an ES group (Binzer, 1999; Stone et al., 2004) or a healthy control group (Goldstein et al., 2000). Research also indicates that patients with PNES perceive their lives as more stressful than healthy control groups (Frances et al., 1999; Marquez et al., 2004; Testa, Krauss, Lesser, & Brandt, 2012). In their study, Testa et al. (2012) found that the type of stressors the PNES patients in their study experienced were not objectively more severe than the stressors of ES patients and the healthy control group. However, they indicated experiencing greater distress caused by these stressors (such as events related to social functioning, work and health status than the other groups). Therefore, it seems worthwhile to investigate coping strategies used by PNES patients to manage stressful events.

Relatively few studies have explored coping strategies among PNES patients (Stanhope, Goldstein, & Kuipers, 2003). Studies indicate that patients with PNES tend to use coping strategies that are more maladaptive and emotion-focused, rather than adaptive, problem-focused coping strategies (Frances et al., 1999; Goldstein et al., 2000; Stanhope et al., 2003; Testa et al., 2012; Zaroff et al., 2004). The most reported coping strategy of PNES patients is escape-avoidance (Frances et al., 1999; Goldstein et al., 2000). Other coping strategies such as distancing (Frances et al., 1999), dissociation (Goldstein et al., 2000) and denial (Stone et al., 2004) have also been reported.

Frances et al. (1999) found that, although the distancing coping strategies reported by PNES patients were comparable to those of an ES group, the PNES patients reported significantly more distancing coping strategies when compared with a healthy control group. According to Lazarus and Folkman (1984), distancing coping may be useful in situations where the demands and expectations of society on the individual are complex (e.g. the various roles that

the individual needs to play). However, Lazarus and Folkman (1984) warn that, if the individual loses his or her "sense of identification or commitment" (p. 238) by using distancing as a coping strategy, it may have a negative effect on the individual's social functioning and health. Distancing strategies may be a useful coping technique for patients with ES to minimize the effect of the diagnosis. However, in the context of a psychological disorder such as PNES, distancing coping strategies may result in avoiding seeking treatment or adhering to treatment (Frances et al., 1999).

Studies indicate that PNES patients demonstrated higher levels of a tendency to dissociate when compared with a healthy control group (Goldstein et al., 2000; Kuyk, Van Dyck, & Spinhoven, 1996; Zaroff et al., 2004). According to LaFrance and Zimmerman (2010), dissociation can be a disorder and/or a mechanism. Dissociation does not form part of one of Lazarus & Folkman's (1984) coping strategies. However, Gross (1983) is of the opinion that dissociation can be regarded as a coping strategy because it protects the individual from traumatic or stressful experiences. Goldstein et al. (2000) reported that dissociation could be correlated positively with emotion-focused coping strategies. Therefore, in PNES patients, dissociation may be considered a maladaptive coping mechanism developed in response to a traumatic or stressful experience (Goldstein et al., 2000; Marquez et al., 2004).

Stone et al. (2004) reported that, compared with ES, patients with PNES have a greater tendency to deny psychological distress and will rather blame their problems on their physical illness (e.g. seizures). According to Caplan and Plioplys (2010), the reason for this may be that the PNES patient struggles to communicate or recognize difficulties other than physical symptoms such as the seizures. On the other hand, Testa et al. (2012) in their study did not find that PNES patients engaged in more denial coping strategies than their healthy control group did. However, they found that PNES patients with higher distress ratings used denial coping strategies more often than the PNES group with low distress ratings did. According to Felsten (1998), denial can be regarded as a type of avoidance coping strategy.

PNES patients tend to avoid rather than approach stressful situations (Krawitz et al., 2001; Zaroff et al., 2004). Research focussing on self-report investigations found that PNES patients were more likely to use escape-avoidant coping styles to manage stress than ES and healthy control groups did (Frances et al., 1999; Goldstein & Mellers, 2006; Goldstein et al., 2000). The findings of a study that investigated PNES patients' automatic threat avoidance tendencies in relation to stress and cortisol levels were in line with the findings of the above-

mentioned self-report studies. They also found that PNES patients showed increased avoidance tendencies to social threat cues (Bakvis, Spinhoven, Zitman, & Roelofs, 2011). According to Baslet (2011), the tendency of avoidance behaviour in individuals might make them more vulnerable to develop PNES.

An avoidance coping style may offer a secondary gain (e.g. avoidance of a situation or not dealing with social difficulties) to the person with PNES. For example, if the person finds it difficult to cope with the stress at work, by having a PNES the person might not need to go to work and in that way avoids the stressful situation. However, the recurrent use of escape-avoidant coping is likely to lead to failure in seeking psychological help and maintain anxiety (Caplan & Plioplys, 2010). Thus, the person is rendered even less able to deal with possibly unbearable difficulties (Lazarus & Folkman, 1984) and is more likely to perceive objectively harmless situations as severely stressful. Therefore, escape-avoidance coping may be a maladaptive coping technique, and PNES may be self-perpetuating (Frances et al., 1999).

Maladaptive coping mechanisms seem to underlie PNES and help to protect the patient from experiencing other intense negative effects that may arise if unresolved or when he/she is confronted with irresolvable situations (Owczarek, 2003). According to Zaroff et al. (2004), PNES is a common reaction to extreme stressors when coping strategies are maladaptive. Also, PNES has been theorized to reflect a learned pattern of avoidant behaviour to deal with stressors (Bakvis et al., 2011). Therefore, PNES can be employed to function as a coping mechanism (Aalsaadi & Marques, 2005).

### **2.12.3 Coping and treatment**

According to Folkman and Lazarus (1988a), coping styles have an important effect on the outcome of the disease. Interventions that focused on enhancing coping strategies that are more effective in managing stress as part of a cognitive behavioural treatment programme for adults were found to be effective (Steinhardt & Dolbier, 2007). In their follow up studies of 4-6 years, Bodde et al. (2007) found a significant reduction in seizure frequency and an improvement in the type of coping strategies that PNES patients used. PNES patients used coping strategies that are less dissociative, and there was a reduction in their passive avoidant behaviour. However, they could not prove that a causal relationship between certain coping strategies and seizure reduction exists. Kuyk et al. (2008) indicated that, after PNES patients had received on average 4.8 months of multidisciplinary treatment, most of the patients experienced seizure reduction and their coping was more adaptive. Another study indicated

significant decreases in dissociative and emotion-based coping mechanisms after PNES patients had received psychotherapy and psycho-education for 10 weeks (Zaroff et al., 2004). Research suggests that the treatment of PNES patients should include methods to ensure adaptive rather than maladaptive coping strategies (Caplan & Plioplys, 2010).

### **2.13 HRQOL and Coping**

Research focusing on chronic illness indicates that coping styles may play a major role in HRQOL (Coelho et al., 2003; Pretorius et al., 2010; Van de Ven et al., 2007). Constructive coping styles may have a positive effect on the quality of life in patients with a chronic disease (De Ridder et al., 2008; Hesselink et al., 2004).

Studies focussing on patients with diabetes found that a greater portion of the patients used avoidance coping styles. They also indicated that avoidance coping strategies were related to lower HRQOL (Coelho et al., 2003; Pretorius et al., 2010). Similarly, studies that focused on patients with asthma (Van de Ven et al., 2007), chronic obstructive pulmonary disease (Hesselink et al., 2004) and inflammatory bowel disease (Van der Zaag-Loonen et al., 2004) reported that avoidant coping was related to lower HRQOL in these patients.

Research that examined the relationship between coping style and perceived HRQOL in epilepsy patients compared with individuals from the general Dutch population found that ES patients tend to use an avoiding coping style more often (Westerhuis et al., 2011). They also reported that 45% of the variance in the mental component of HRQOL was explained by a passive coping style, which was more important than other seizure-related measures. This indicates that the patient's coping style may be more important than seizure frequency in predicting the mental aspects of HRQOL.

It seems as if avoidance coping may be associated with lower HRQOL in chronic diseases. PNES is a debilitating disease that necessitates several adjustments in a patient's life, and it may also become chronic. The preceding review of literature on PNES suggests that avoidance coping is a prominent coping strategy for PNES patients (Mercer et al., 2010). Moreover, research has shown that PNES patients' scores on the HRQOL measure are significantly lower than those of epilepsy and healthy control groups (LaFrance et al., 2011). It is evident that PNES has a great effect on an individual's well-being, but often seizure frequency does not explain self-reported quality of life. Therefore, it can be hypothesized that an individual's personal coping style may play an important role in his/her quality of life. However, no research that studied the association between specific coping styles and

HRQOL of PNES patients could be found. Therefore, the primary aim of this study is to explore if a possible relationship between coping styles and the HRQOL of PNES patients exists.

## **2.14 Theoretical framework**

This study will be conceptualised within the framework of Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping. This is also the theoretical framework used by most of the previous research that focused on coping strategies in PNES patients (Frances et al., 1999; Goldstein et al., 2000) and research focussing on coping strategies and HRQOL in chronically ill patients (Van der Zaag-Loonen et al., 2004; Van Rhenen et al., 2008; Welch & Austin, 2001).

According to Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, cognitive appraisal and coping play a mediating role in the emotional outcome of a threatening event. In other words, "the quality of life and what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (Lazarus & Folkman, 1984, p. 181). Depending on the quality and intensity of the emotional outcome, it may affect the subjective well-being (morale), social functioning and somatic health of an individual in the long term (Lazarus & Folkman, 1987).

Emotion needs to be understood in the context of the relationship between the person and the environment. It cannot be understood only in terms of a response to an environmental stimulus (externally) or only from the standpoint of the person (psychological characteristics). An event is threatening only when the person has personal variables that make him/her vulnerable to the situation and relevant conditions in the environment may prevent the person from achieving his/her goal. For example, an examination can be experienced as threatening if it is important for the individual to do well so that he will be selected for a postgraduate programme. In a threatening event, an individual will employ a particular coping strategy based on how it will affect his/her well-being (appraisal) and his/her ability to control or deal with it. Therefore, the intensity and quality of an emotion depends on the process and the mediating variables, cognitive appraisal and coping (Lazarus & Folkman, 1987).

In their system approach to stress and causal antecedents to coping, the mediating process and emotion outcome are seen as the most important variables that interact to produce the

adaptational patterns and state of mind that characterize a stressful transaction. An adapted theoretical schematization is presented in Figure 1.

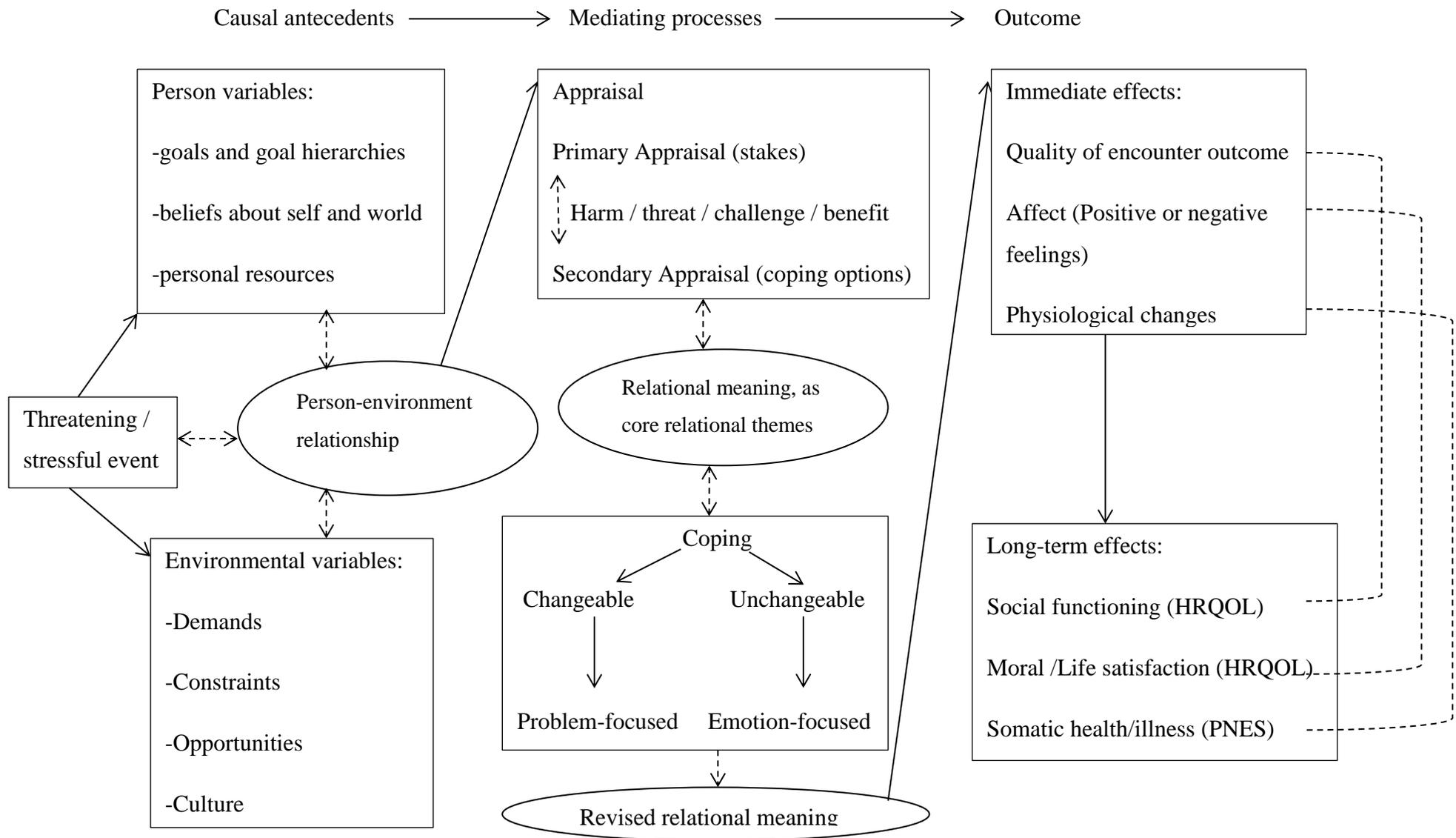


Figure 1. Model of stress and coping (adapted from Folkman et al., 1991; Lazarus & Folkman, 1984, 1987; Lazarus, 1999).

### **2.14.1 Causal antecedents**

Personal variables and environmental variables can be regarded as antecedent conditions of appraisal. Personal variables interact with environmental variables, which in turn influence our reactions via the process of appraisal. The three key personal variables that an individual uses in shaping appraisal are goals and goal hierarchies, beliefs about self and the world, and personal resources. Goal and goal hierarchies refer to the implication of an encounter for one's personal goals. Stress emotions or negatively toned emotions arise if there is a possibility that an event will prevent the person from achieving his/her goal. How an individual conceives him-/herself and his/her place in the environment (e.g. chances of mastering the encounter and expectations of the outcome) are referred to as beliefs about self and the world. The third personal variable is personal resources with which the environmental variables interact. It influences the chances of successful adaptation and can include social skills, education, intelligence, money, supportive family and friends, physical attractiveness, health, energy, etc. (Lazarus & Folkman, 1984, 1987).

The four important environmental variables that influence emotion are demands, constraints, opportunities and culture. Demands refer to implicit or explicit pressures from the social environment to act in a prescribed way or to conform to social conventions. Constraints, on the other hand, refer to the prohibited way of acting (e.g. when you cope with stress in a way that violates social standards). Opportunity, the third environmental variable that influences the process of appraisal, refers to choosing the most opportune social setting in which to live and work in order to forecast a favourable adaptational outcome. The culture in which an individual grows up also plays a role in the mediating process (Lazarus & Folkman, 1984, 1987).

### **2.14.2 Mediating process**

The two basic constructs (variables) central to Lazarus and Folkman's (1984) theory cognitive appraisal and coping. Appraisal is the process through which an individual evaluates how what is happening to him/her will affect his/her well-being. The way we cope and the emotional outcome flow from this appraisal. There are two kinds of cognitive appraisal, namely primary appraisal and secondary appraisal.

Primary appraisal refers to whether or not what is happening is relevant to the personal variables (goal commitments, beliefs about self and the world, and situational intention). The person decides if something of importance to his/her well-being is at stake in the encounter to

arouse a stress reaction. There are three types of primary appraisals of stress, namely harm, threat and challenge. Harm refers to something already experienced (e.g. harm to a friendship). A threat is harm that is anticipated, and a challenge refers to the potential for gain or mastery of the obstacle. The intensity of the stressful appraisals depends on the relationship between the personal significance of the goal commitment that has been harmed, threatened or challenged and the adequacy of the person's resources to manage the harm, threat or challenge.

Secondary appraisal refers to a cognitive evaluation process that evaluates if anything can be done (which coping options might work) about a stressful person-environment relationship, especially when there has been a stressful primary appraisal (e.g. harm, threat, or challenge) (Lazarus, 1999). The individual evaluates any changes in the person-environment relationship. Based on these changes and on the adaptation outcome of the coping process, the individual will constantly reappraise the situation. This reappraisal may change the construction of the person-environment relationship and subsequent coping efforts (Folkman, Chesney, Mckusick, Ironson, Johnson, & Cates, 1991).

Coping can be regarded as a process since people strive to change what is distressing (Lazarus, 1993). If an individual believes that the threatening event can be defeated, coping strategies that are more problem focused emerge with a response tendency to fight back. On the other hand, if an individual believes that he/she is unable to control the threatening event, or that the event is unchangeable, the individual will look for possibilities of escape and use coping strategies that are more emotion-focused. As discussed in section 2.12, problem-focused coping includes confrontive coping, self-controlling, seeking social support and planful problem-solving processes. Emotion-focused coping includes escape-avoidance, distancing, accepting responsibility and positive reappraisal processes. Refer to Table 2 for a description of each of the processes. If we use the example of the examination (which was described earlier), the student may experience much stress or anxiety at the beginning of the test, but if the student believes in his/her academic ability, regulates his/her feelings of anxiety and turns his/her attention to the task (problem-focused coping), it will reduce his/her feelings of distress. An example of emotion-focused coping will be if the student believes that he/she is unable to pass the test and therefore decides not to write the test. According to Lazarus and Folkman (1984), "in effective coping, problem- and emotion-focused forms of coping will work in a complementary fashion and not impede each other" (p. 223).

Whether coping is effective or not depends on the match between the reality of the person-environment transaction and the person's appraisal of that transaction. It also depends on the match between secondary appraisal and the coping process. There must be a good fit between other personal agendas (i.e. values, goals, commitments and beliefs) and the coping efforts that are used in the encounter. Furthermore, the individual must also be effective in his or her coping skills to achieve the desired emotional outcome (e.g. problem-solving skills, communication skills, achieving desired physical states such as relaxation or meditation, cognitive restructuring and distancing). A poor fit may decrease the possibility of managing or reducing distress and could even lead to increased distress (Folkman et al., 1991).

### **2.14.3 Emotional Outcome**

According to Lazarus and Folkman's (1984) theory, long-term emotional outcomes are generally categorised as functioning in work and social living (social functioning), morale or life satisfaction (morale) and somatic health. Each one of these long-term adaptational outcomes has a counterpart in the immediate effect (short-term) right after a stressful encounter or event. However, even though there are parallels between the immediate and long-term effects, it does not imply there is only a one-to-one relationship between the outcome of a stressful encounter and its long-term counterpart.

Social functioning can be regarded as the way in which the individual fulfils his or her various roles (e.g. partner, parent, community member and employee). The quality of the encounter outcome can be regarded as the short-term outcome of social functioning. The quality of the outcome refers to the effectiveness with which the demands of day-to-day living were managed (i.e. whether the situation was improved, worse or the same after the encounter). Social functioning in the long-term can be regarded as the coping effectiveness of the person in many specific encounters during the course of his/her life (Lazarus & Folkman, 1984, 1987).

Morale refers to how people feel about themselves (e.g. subjective well-being) and their life conditions (i.e. life satisfaction). The positive and negative emotions (affect) that individuals experience during a stressful encounter can be regarded as the short-term outcome that is generated in a specific encounter. Negative emotions refer to stress, fear, anger, guilt and shame, whereas joy, happiness, pride, love and relief are positive emotional responses (Lazarus, 1993). The long-term outcome of morale depends on the performance outcome as well as the expectations regarding the performance outcome. For example, an individual will

have a positive sense of well-being if he/she is satisfied with the goal that has been achieved and with his/her performance during the encounter.

The counterpart of somatic health in the short term refers to the physiological changes (i.e. heart pounding faster) generated by a stressful encounter. In their theory, Lazarus and Folkman (1984) suggest that coping may affect somatic health via three routes. First, coping can influence the intensity, frequency, duration and pattern of neurochemical stress reactions. This can be done by using ineffective coping strategies or by "expressing a set of values and a corresponding lifestyle and/or coping style that in itself is consistently mobilizing in a harmful way" (Lazarus & Folkman, 1984, p. 215). Second, if a person uses excessive injurious substances such as drugs, alcohol or tobacco to cope with stress, it can increase the risk of mortality and morbidity. Third, emotion-focused coping can impair health by hindering adaptive health-/illness-related behaviour, for example if a person uses only avoidance or denial as a coping strategy. The use of avoidance or denial may lower emotional distress, but can prevent the person from realistically addressing the problem in a suitable way.

#### **2.14.4 Theory related to PNES**

In this theory, stress and coping are proposed to affect adaptational outcomes. In accordance with this model, it is possible that PNES patients will perceive the demands of life as unbearably stressful (LaFrance & Bjørnes, 2010; Tojek et al., 2000) and out of their control (Stone et al., 2004). Such individuals might be expected to employ avoidant and distancing coping strategies rather than planful, problem-focused strategies in their approach to managing stressful situations. Therefore, they will constitute more maladaptive, emotion-focused (avoidance or distancing) coping strategies to cope with a threatening event. The use of maladaptive, emotion-focused coping can affect their somatic health and contribute to the development of PNES. As PNES appears to be a mechanism for avoiding responsibility and escaping from stressful situations, this notion also has intuitive appeal. The current study specifically hypothesizes that people with PNES are more likely to use emotion-focused coping strategies such as escape-avoidant and distancing coping strategies and less likely to use planful problem-solving coping strategies than people who do not have PNES.

To make the theory more practical, it will be explained by means of an example. Because PNES patients are a very heterogeneous group and do not have a single psychological aetiology (Alsaadi & Marquez, 2005; Bodde et al., 2009; Lezak et al., 2004; Quinn et al., 2010; Reuber

et al., 2007), the stressful/threatening event will vary between patients. Conflict in the family, emotional or sexual abuse, trauma or the loss of a loved one are examples of events that may be experienced as threatening or stressful. For the purpose of this discussion, the example of a 17-year-old girl who needs to choose a career to follow after school will be used. She wants to become an artist, but her parents want her to become a medical doctor.

According to this theory, the career choice itself might be perceived as a stressful event (refer to *Threatening / stressful event* in Figure 1). Her goal (refer to *Personal variables: Goals and goal hierarchies* in Figure 1) is to become an artist, but her parents (refer to *Environmental variables: Demands* in Figure 1) want her to be a medical doctor. She is unsure if she will be good enough as an artist to make a living out of it, and it is very important for her to please her parents (refer to *Personal variables: Beliefs about self and the world* in Figure 1). In her culture, it is expected of children to respect their parents and do as they say (refer to *Environmental variables: Culture* in Figure 1). She does not have the financial resources (refer to *Personal variables: Resources* in Figure 1) to pay for her own studies and therefore depends on her parents to pay for her studies (refer to *Environmental variables: Constraints* in Figure 1). This interplay between her personal and environmental variables is referred to as the *Person-environment relationship* in Figure 1.

The girl will then evaluate the *person-environment relationship* with respect to its significance (refer to *Primary appraisal* in Figure 1) and resources. Choosing a career will be perceived as threatening if the girl believes that her parents will prevent her from achieving her goal of becoming an artist. As it is also important for her to please her parents and to live up to the expectations of others, these environmental demands create conflict within her between her personal goals and her beliefs. This inner conflict leads to psychological stress, and the girl then needs to decide on how she is going to cope with it (refer to *Secondary Appraisal* in Figure 1). She will then assess her career options based on the expected outcome of each (refer to *Relational meaning, as core relational themes* in Figure 1). If she believes that she does not have the necessary communication skills to convince her parents otherwise without disappointing them (refer to *Coping: Unchangeable* in Figure 1), she then decides to become a medical doctor. By choosing the career option her parents favour, she is avoiding the problem (refer to *Coping: Emotion-focused* in Figure 1).

While the girl is making her career choice and after she has made the decision, she may feel stressed and angry (refer to *Immediate effects: Affect/distress* in Figure 1). However, in the long term, not following a career that she wanted may affect her satisfaction with life (refer to

*Long-term effects: Morale* in Figure 1). It may also lead to the development of PNES if the conflict in her unconscious remains unresolved (refer to *Long-term effects: Somatic health / illness* in Figure 1).

According to this theory, once the girl has developed PNES, the fear of having another PNES might also be perceived as a stressful event. The PNES patient might appraise the encounter as a threat and unchangeable. It is then likely that he/she will use more emotion-focused coping, which in the short term may provoke negative emotions such as stress, fear or anxiety. In the long term, the recurrent experience of unpredictable PNES might result in feelings of dissatisfaction within the individual. This may have a negative effect on the well-being of the person and result in low quality of life. The current study also hypothesizes that people with PNES experience lower quality of life than people who do not have PNES.

## **2.15 Conclusion**

This chapter provided more background to PNES and the research related to PNES. From the literature reviewed, it is clear that, although the prevalence rate of PNES is relatively low in the US and Europe and even unknown in South Africa, PNES is more common at epilepsy-monitoring units than one would expect. The negative impact PNES has on the HRQOL of these patients has been discussed. The role that certain coping strategies (such as avoidance coping) play in the development of PNES has also been highlighted. The chapter also highlighted the influence coping strategies may have on the HRQOL of patients and indicated that HRQOL and coping styles should be considered in the treatment of PNES patients. However, to date, research that focuses on the association between HRQOL and coping styles in PNES patients is still lacking.

The research objectives, the recruitment of the participants, informed consent procedures, method of data collection, data analysis and ethical considerations are discussed in the next chapter.

## Chapter 3 Research Design and methodology

### 3.1 Research objective and specific research questions

The primary aim of this study was to explore a possible association between coping styles and the HRQOL of patients with PNES. To achieve the aim of the study, the following research questions were formulated:

1. What is the level of HRQOL in patients with PNES compared to a healthy control group?
2. What are the differences between the kinds of coping strategies used by patients with PNES and those used by participants in the healthy control group?
3. What is the association between the specific coping strategies of patients with PNES and their HRQOL?

### 3.2 Research design

This was a quantitative cross-sectional study.

### 3.3 Participants

By means of convenience sampling, 44 participants were recruited to participate in this study. The sample consisted of two groups, namely PNES patients ( $n = 22$ ) and a healthy control group ( $n = 22$ ). Even though most of the PNES studies compare PNES patients with ES as a control group, the validity of such a comparison is questionable, given that other psychological factors may play a role in PNES (Mercer et al., 2010). Birbeck and Vickrey (2003) argue that, only because PNES and ES may appear similar, one cannot assume that the personal experiences of PNES and ES patients are identical. Therefore, it was decided rather to compare PNES patients with a healthy control group than an ES group. The sample size of this study seems to correspond with the low prevalence rate of PNES and sample sizes that generally vary between 20 and 30 participants in previous PNES research (Bodde et al., 2009).

The participants had to be South African and 14 years or older. The eligibility criterion for each PNES participant was a confirmed diagnosis of PNES by an experienced neurologist based on the results of VEEG. PNES patients with comorbid epilepsy were excluded from the study. Participants in the healthy control group were matched with the PNES group with regard to age and gender. They were excluded from the study if they had a history of seizures

of any kind and/or have been diagnosed with a psychiatric/psychological disorder within the past year.

### **3.3.1 Recruitment of the participants**

#### *3.3.1.1 PNES patients*

PNES patients were recruited from the Epilepsy Unit at the Constantiaberg Medi-Clinic and the Department of Neurology at the Tygerberg Hospital. These hospitals were selected because access to participants in both these regions is convenient, and both hospitals have specialised VEEG equipment to diagnose patients with PNES. The Epilepsy Unit at the Constantiaberg Medi-Clinic has several VEEG monitoring units, whereas the Tygerberg Hospital has only one VEEG monitoring unit.

#### *3.3.1.2 Healthy control group*

Participants in the healthy control group were recruited to match each new PNES participant with regard to age and gender. The reasons for this recruitment technique were the heterogeneity of the PNES group as well as the unknown prevalence rate of PNES in South-Africa, which made it difficult to determine the type (age and gender) and number of participants to select for the healthy control group beforehand. Advertisements and flyers (see Appendix 12) were used to attract participants for the healthy control group. The advertisements and flyers were put up at the private practice of a general practitioner in Wellington and at Stellenbosch University.

## **3.4 Data-collection methods**

### **3.4.1 Material**

A survey consisting of a demographic questionnaire and three self-report instruments was used to collect data related to HRQOL and coping strategies from both these groups. The three self-report instruments have been used in South-African studies before (Benitha & Tikly, 2007; Garzouzie, 2011; Karachi, 2005; Madu & Roos, 2006). The data-collection material was available in English and Afrikaans. A back-translation procedure was used to translate the questionnaire and measurements. The material was not translated into isiXhosa because most of the PNES patients previously diagnosed could speak either English or Afrikaans (J. Butler, Personal communication, 30 June 2011).

### 3.4.1.1 Demographic questionnaire

A self-developed demographic questionnaire (see Appendix 1 for PNES patients and Appendix 2 for the healthy control group) was used to obtain the information required for descriptive purposes and to determine demographical variables of PNES patients in the South-African context.

### 3.4.1.2 The SF-36v2 Health Survey

The most commonly used HRQOL measures in PNES studies are the SF-36 and the Quality of Life in Epilepsy Inventory (QOLIE) questionnaires (e.g. QOLIE-89, QOLIE-31, QOLIE-10) (Birbeck & Vickrey, 2003; Mercer et al., 2010; Quigg et al., 2002; Szaflarski et al., 2003a; Szaflarski & Szaflarski, 2004). I chose to use the SF-36v2 to measure HRQOL for this study because it is a generic instrument that can be used across different disease types and because a disease-targeted measure such as one of the QOLIE questionnaires "can rarely be used in samples without the targeted condition" (Birbeck & Vickrey, 2003, p. 141) and therefore would not be appropriate to use with the healthy control group.

The SF-36v2 (Ware et al., 2007) is the revised version of the SF-36 (Ware & Sherborne, 1992), which is a 36-item self-report questionnaire. This questionnaire is designed as a generic health measure and can be used as an outcome measure in clinical practice and research (see Appendix 3). The SF-36 measures both physical and psychological health. It is suitable for individuals of 14 years and older. The SF-36 includes multi-item scales to measure the following eight health dimensions: (a) physical functioning, (b) general health, (c) bodily pain, (d) vitality (energy/fatigue), (e) mental health (emotional well-being), (f) social functioning, (g) role limitation – physical, (h) role limitation – emotional. Responses are entered on a Likert scale. Depending on the number of options per item, each set of options per item is scored between one and six.

All scores were entered into the electronic scoring software (QualityMetric Health Outcomes™ Scoring Software 4.5), which automatically scored the data using the published scoring algorithms of QualityMetric. The scoring program transforms the answers of each question into scaled scores from 0 to 100 (where 100 will indicate optimal health) so that comparisons could be made across the eight subscales. The published mean score for the U.S. general population is 50 ( $SD = 10$ ). Higher scores (above 50) indicate higher HRQOL. Published reliability statistics (internal consistency) for the SF-36v2 have exceeded Cronbach's alpha ( $\alpha$ ) of above .80 (Ware, 2011), which is higher than the acceptable rate of  $\alpha$

= .70 (Field, 2005). Studies have yielded evidence of content, concurrent, criterion, construct and predictive validity (Ware, 2011). A non-commercial licence (Licence no. QMO13316) was obtained from the QualityMetric office of grants and scholarly research for the use of the SF-36v2 questionnaire.

#### 3.4.1.3 *Ways of Coping Questionnaire (WOC)*

The WOC (Folkman & Lazarus, 1988b) (see Appendix 4) assesses categories of coping described in Lazarus and Folkman's theory of stress and coping (Lazarus & Folkman, 1984) which forms the theoretical framework for this study. The WOC consists of 66 items measuring eight coping strategies: escape-avoidance, distancing, accepting responsibility, positive reappraisal, confrontive coping, self-controlling, seeking social support and planful problem solving. Respondents are asked to think of a specific stressful event in the past four weeks and indicate the extent to which they used each strategy to cope with it. Responses are entered on a 3-point Likert scale (0 = *does not apply or not used* and 3 = *used a great deal*). The total score was calculated by adding the participant's responses to the items that comprised a given scale. The psychometric properties of the scale researched and it is considered a reliable (the average  $\alpha$  on all subscales is above .70) and valid instrument (Folkman & Lazarus, 1988a, 1988b; Skinner et al., 2003). The WOC have been used in South-African studies before (Madu & Roos, 2006).

#### 3.4.1.4 *Coping Strategy Indicator (CSI)*

The CSI (Amirkhan, 1990) (see Appendix 5) is a 33-item scale that addresses a range of coping strategies (problem- and emotion-focused) that an individual might use in a stressful situation. It is designed to measure three subscales of coping strategies, namely problem solving, seeking social support and avoidance. Avoidance coping is emotion-focused, and problem solving refers to problem-focused coping strategies. Social support can be either emotion- or problem-focused. For example, a person may ask a friend to help him search for a solution to his/her problem, which can be regarded as problem-focused coping. Conversely, the same person may want to cry on a friend's shoulder, which can be regarded as emotion-focused coping (Welch & Austin, 2001).

Respondents are asked to select a stressful event in the past six months and briefly describe it. They respond on a 3-point Likert scale anchored at "*not at all*" and "*a lot*", indicating the extent to which they used each of the coping strategies to deal with the stressful event. To score the results, a numerical score was assigned to each response (1 = *not at all* and 3 = *a*

lot). The scores of each question were then entered into the appropriate subscale and summarised to provide the total score per subscale. According to Amirkhan (1990, 1994) the mean and standard deviation scores of the CSI subscales for a normative sample are as follows; *seeking social support* (mean = 23.42, *SD* = 5.63), *problem solving* (mean = 26.55, *SD* = 4.82) and *avoidance* (mean = 19.03, *SD* = 4.37). The Cronbach's alpha coefficient indicated a high internal consistency reliability of above .84 for all subscales. Strong construct, discriminant and criterion validities have also been reported (Amirkhan & Auyeung, 2007; Amirkhan, 1990; 1994).

Two different coping instruments (WOC and CSI) were used to determine the coping strategies of the participants. The WOC was the primary coping instrument, because it is constructed on the theoretical framework of Lazarus and Folkman's theory of stress and coping (Lazarus & Folkman, 1984), which formed the basis of this study. It was decided to use an additional coping instrument to support and/or verify the results of the WOC. The CSI was selected primarily as the additional coping instrument because it has been used successfully in other South-African studies (Garzouzi, 2011). Secondly, in line with Lazarus and Folkman (1984), it also measures problem-focused and emotion-focused coping strategies.

### **3.4.2 Procedure**

Data collection took place from October 2011 until June 2012. PNES patients attending the Epilepsy Unit at the Constantiaberg Medi-Clinic or the Department of Neurology at the Tygerberg Hospital for assessment or treatment were informed by the neurologist or health care professionals of the opportunity to participate in the study. With the permission of the patients who indicated an interest to participate in the study, their contact details were given to the researcher. The researcher then personally or telephonically approached the patient and his/her parents/legal guardian (if the patient was younger than 18 years) and explained the study to him/her. Once the patient agreed to participate in the study and was 18 years and older, he/she was asked to sign an informed consent form (see Appendix 6). For patients younger than 18 years, the parents had to complete an informed consent form (see Appendix 7), and the patient had to complete an informed assent form (see Appendix 8).

The volunteers for the healthy control group contacted the researcher. When their description matched those of the PNES patients, they were invited to participate in the study. When a volunteer indicated that he/she was willing to participate in the study and was 18 years and

older, he/she was asked to sign an informed consent form (see Appendix 9). For patients younger than 18 years, the parents had to complete an informed consent form (see Appendix 10), and the patient had to complete an informed assent form (see Appendix 11).

After all the necessary informed consent forms had been completed, the participants were presented with a survey consisting of a demographical questionnaire (see Appendix 1 for PNES patients and Appendix 2 for the healthy control group) followed by the self-report instruments, namely the SF-36v2 (see Appendix 3), the WOC (see Appendix 4) and the CSI (see Appendix 5). If the participants were still hospitalised during their participation in the study (which was sometimes the case in the PNES group), the researcher delivered the survey to them in person; otherwise, the researcher e-mailed the survey or posted a hard copy to the participants. The primary researcher provided instructions on completing the survey. The completion of the survey did not take longer than 45 minutes. After completion of the survey, the participant had to e-mail/post it back to the researcher, or the researcher collected it at the hospital.

### **3.5 Data analysis**

The data analysis was undertaken using the Statistical Package (STATISTICA version 10). The quantitative data analyses were conducted with the assistance of a qualified statistician. The results of the demographic questionnaire are summarised and are reported in chapter 4. Descriptive statistics were calculated to determine the mean age of the sample. The Chi-square test was used on the relevant categorical data to determine if there was a significant difference between the responses of the PNES group and the control group on the following two demographic questions: "*Do you perceive your life as stressful?*" and "*Do you sometimes struggle to cope with stressful situations?*"

Descriptive statistics (means and SDs) on all the subscales of the three self-report instruments (SF-36v2, WOC and the CSI) were calculated. The internal consistency of each subscale was also determined by means of a reliability analysis, using Cronbach's alpha ( $\alpha$ ).

The first research question, which focused on the level of HRQOL, was dealt with using the univariate one-way analysis of variance (ANOVA) (Field, 2005) to explore whether there were significant differences between the mean scores of the healthy and the PNES groups on the SF-36v2. Furthermore, a mixed-model repeated measures ANOVA was conducted to investigate the tendency of PNES patients to report significantly lower levels on the *role limitation – physical* subscale than on the *physical functioning* subscale of the SF-36v2.

According to the literature, this trend is evident only among PNES patients and not among the control groups of several studies (Al Marzooqi et al., 2004; Lawton et al., 2008; Testa et al., 2007).

The second research question (dealing with the different kinds of coping strategies) was analysed using the univariate one-way ANOVA to investigate the differences in each of the coping strategies between the mean scores of the PNES and the control groups.

The third research question, which examined the association between the specific coping strategies of patients with PNES and their HRQOL, was dealt with by using correlation and regression analyses. To investigate the association between specific coping strategies and HRQOL, a correlation analysis was done by calculating Pearson's correlation coefficients. A regression analysis was conducted to investigate the extent to which HRQOL (dependent variable) could be explained by coping strategies (independent variable) that were used by the participants.

### **3.6 Ethical approval**

Ethical approval was obtained from the Health Research Ethics Committee at the Stellenbosch University (refer to Appendix 13), the Constantiaberg Medi-Clinic (refer to Appendix 14) and Tygerberg Hospital (refer to Appendix 15). The nature of the study was explained to each participant either telephonically or in person. They were assured of their anonymity and the confidentiality of their contributions to the research. They were also assured that the completed forms would be kept safe at Stellenbosch University and that only my supervisor and I would have access to the data. They were informed that no risks were involved for participating in this study, but in the event of the questions bringing some unforeseen emotions to the fore, participants would be provided with the contact details of professionals to whom they could turn for support or therapy. They were also informed that no compensation would be paid to them for participating in the study and that they could withdraw from the study at any time without any consequences. Once the participants had verbally confirmed their wish to participate in the study, they were requested to sign a written informed consent form prior to the commencement of the research. For participants younger than 18 years, the parents had to complete an informed consent form and the participants an informed assent form. These forms described the goals of the research, the participants' roles and responsibilities during the research process, as well as the expected outcomes and issues relating to the dissemination and publication of the results of the study.

### **3.7 Conclusion**

This chapter outlined the research design and methodology of this study. The primary aim of the study and the specific research questions were highlighted. The recruitment of the participants, data collection, data analyses and ethical considerations were discussed in this chapter. The results of this study are discussed in the following chapter.

## Chapter 4 Results

### 4.1 Introduction

The results of the study are presented and discussed in this chapter. The demographic results will be discussed first. Second, the descriptive statistics of the various measuring instruments and subscales will be reported. Next, the results of the univariate one-way ANOVA for the PNES and Healthy control group on the HRQOL (SF-36v2) and the coping measuring instruments (WOC and CSI) will be presented. Finally, correlation and regression analyses between these various constructs will be presented.

### 4.2 Demographic results

In total, 25 patients with a confirmed VEEG diagnosis of PNES were referred to the researcher during the data-collection period. Most of the PNES patients ( $n = 21$ ) were referred by the neurologist at the Epilepsy Unit of the Constantiaberg Medi-Clinic. Of the 25 PNES patients that were referred to the researcher, only three patients did not participate in the study, which means that the study had a participation rate of 88%.

The participants in the healthy control group were matched with each PNES participant with regard to age and gender. Table 3 below provides a summary of the gender and age distribution of PNES group and the healthy control group.

Table 3

*Gender and Age of the PNES and Control Groups*

	PNES ( $n = 22$ )	Control ( $n = 22$ )
<i>Sex</i>		
Female	17	17
Male	5	5
<i>Age in years</i>		
Mean	32.77	32.77
SD	14.40	14.68
Range	14 - 55	14 - 59

It is evident from Table 3 that most of the PNES participants (77%) were female, whereas only 23% (5 of the 22) were male. The mean age of the PNES group was 32.77 years (with a SD of 14.40). However, the age distribution of the sample was bimodal. To illustrate this, Figure 2 below shows the two distinct peaks of the age distribution of the PNES group.

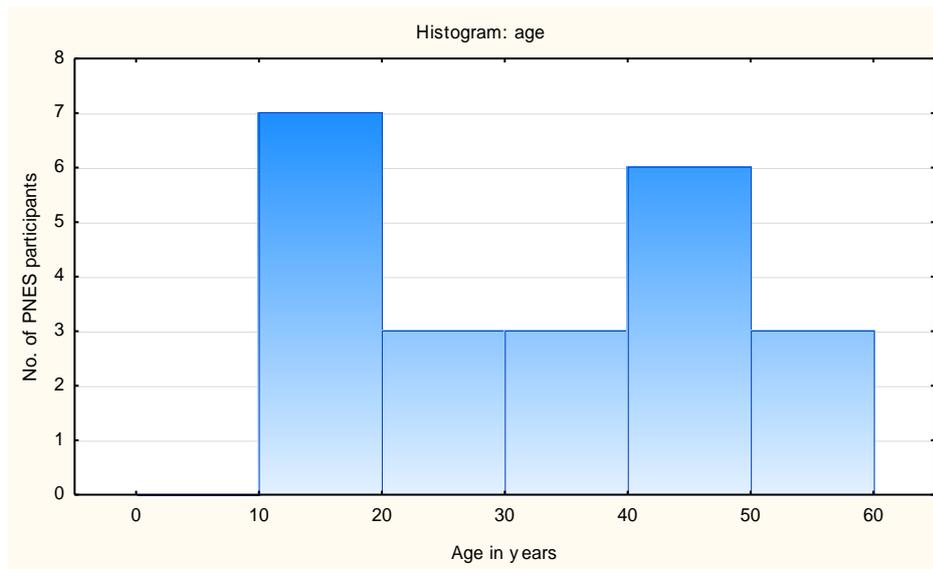


Figure 2. Age distribution of the PNES group ( $n = 22$ ).

In the PNES group, seven (32%) of the participants were between the ages of 14 and 18 years, and most of them were 17 years old, as indicated by the first bar of the histogram in Figure 2. The age group between 40 and 50 years represents 27% (6 of 22) of the PNES group.

Additional demographic information of the PNES group is summarised in Table 4 below.

Table 4

*Demographic information of PNES and Control Groups*

	PNES ( $n = 22$ )	Control ( $n = 22$ )
<i>Ethnicity</i>		
Black	-	-
Caucasian	15	20
Coloured	7	2
Indian	-	-
<i>Home Language</i>		
Afrikaans	11	22
English	10	-
Xhosa	-	-
Other (Portuguese, but fluent in English)	1	-

Table 4 *Continued*

	PNES (n = 22)	Control (n = 22)
<i>Marital status</i>		
Single	10	11
Married	11	11
Divorced	1	-
<i>Education level</i>		
Before grade 12	11	7
Grade 12	5	2
Tertiary diploma	2	2
Degree at university	3	11
<i>Employment status</i>		
Unemployed	6	2
Full-time employed	8	8
Part-time employed	-	3
Homemaker	1	2
Medically retired	1	-
Retired	-	-
Student	6	7
<i>Household income</i>		
Low income	4	1
Middle income	13	13
High income	5	5
<i>Do you have any disabilities?</i>		
Yes	5	-
No	17	22
<i>Do you receive a disability grant?</i>		
Yes	1	-
No	21	22
<i>Have you been diagnosed with a psychiatric disorder in the past year?</i>		
Yes	6	-
No	16	22
<i>Have you had any kind of seizure before?</i>		
Yes	14	-
No	8	22
<i>Have you been diagnosed with epilepsy before?</i>		
Yes	7	-
No	15	22

Table 4 *Continued*

	PNES (n = 22)
<i>How long did it take before you were diagnosed with PNES? <sup>a</sup></i>	
Less than 1 year	12
1-2 years	3
2-3 years	2
3-4 years	2
4-5 years	-
5-6 years	-
6-7 years	-
More than 7 years	3
<i>How often do you have seizures? <sup>a</sup></i>	
More than once a day	8
Once every day	3
More than once a week	6
Once a week	2
Every 2nd week	2
Once a month	-
Once a year	-
<i>Are you currently receiving any treatment? <sup>a</sup></i>	
Yes	8
No	14
<i>What type of treatment are you receiving? <sup>a</sup></i>	
Psychodynamic therapy	6
Cognitive behavioural therapy	1
Anxiety medication	1
<i>Would you like to be part of a support group? <sup>a</sup></i>	
Yes	15
No	7
<i>Would you like to receive your support individually or in a group? <sup>a</sup></i>	
Individually	3
Group	11
<i>What type of other support would you like? <sup>a</sup></i>	
More information	7
Telephonic	3
Website	5
Talk to someone who had PNES	12

Note: <sup>a</sup> These questions were applicable to the PNES group only.

It is apparent from Table 4 that 68% (15 of the 22) of the PNES participants were Caucasian and 32% Coloured. Half of the participants' home language was Afrikaans, and 45% were English-speaking. Seven of the PNES participants were still at school. Of the PNES participants that were not at school or studying, only 53% were employed full-time, whereas 40% were either unemployed or medically retired. Most of the PNES participants viewed their household income to fall within the middle-income group. Only 32% (7 of 22) of the participants had been diagnosed with epilepsy before. For half of the PNES participants, it took less than a year before they were diagnosed with PNES. For 32% of the PNES group, it took between one and four years. Only 14% of the PNES participants indicated that it had taken them more than seven years to be diagnosed with PNES. Half of the PNES group had one or more than one seizure per day. Most of the PNES participants indicated that they were not receiving any psychological treatment. Those who were receiving treatment were mostly receiving psychodynamic therapy. More than half of the PNES participants indicated that they would like to be part of a support group and receive support from someone who had been diagnosed with PNES before.

Figure 3 below indicates the response of the PNES group ( $n = 22$ ) and the control group ( $n = 22$ ) to the following question that was included in the demographic questionnaire: *Do you perceive your life as stressful?*

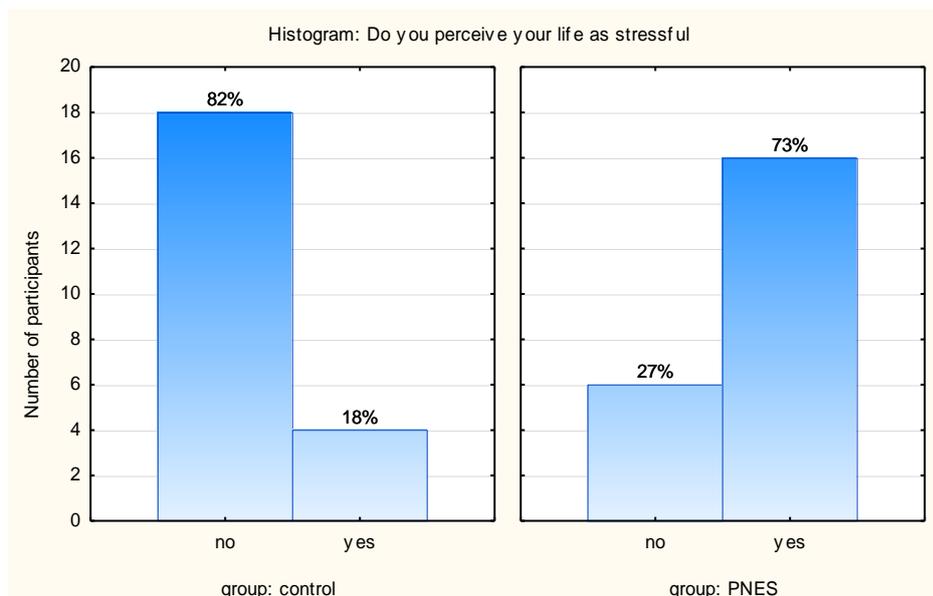


Figure 3. Percentage of participants in the PNES and control groups that perceive their lives as stressful.

Figure 3 above reveals that the majority of the PNES group (73%) perceived their lives to be stressful, whereas only 18% of the control group felt the same way. A Chi-square test was used to determine whether this difference between the perception of the PNES group and the control group about the level of stress in their lives was significant. A Chi-square test produced  $X^2(1) = 13.99$ , which was statistically significant at  $p < .01$ . This shows that the participants in the PNES group perceived their lives to be significantly more stressful than the participants in the control group did.

Figure 4 below indicates the responses of the PNES group ( $n = 22$ ) and the control group ( $n = 22$ ) to the following question: *Do you sometimes struggle to cope with stressful situations?*

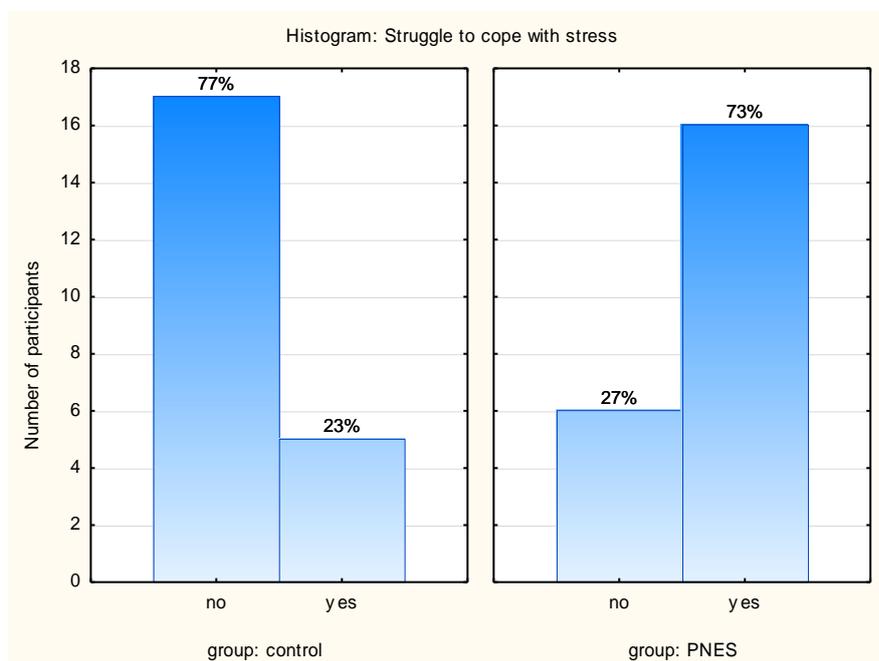


Figure 4. Percentage of participants in the PNES and control groups that struggle to cope with stress.

From figure 4 above, it is clear that 77% of the participants in the PNES group indicated that they struggled to cope with stressful situations, whereas only 23% of the control group seemed to struggle to cope with stressful situations. The Chi-square test produced  $X^2(1) = 11.54$ , which was statistically significant at  $p < .01$ . This indicates that the PNES group struggled significantly more to cope with stressful situations than the control group did.

### 4.3 Descriptive statistics

The skewness and kurtosis of the data were calculated, and it indicated that the data were distributed normally; therefore, parametric tests were used. Internal consistency was determined for each of the instruments (SF-36v2, WOC and CSI) by means of reliability

analyses using Cronbach's alpha coefficients ( $\alpha$ ). A Cronbach alpha coefficient should be equal to at least 0.7 before the measures in question can be considered to possess adequate levels of internal consistency (Field, 2005). The mean, standard deviation and  $\alpha$  for the sample as a whole ( $N = 44$ ) for each of the three measuring instruments are summarised in Table 5.

Table 5

*Cronbach's Alpha for the SF-36v2 Healthy Survey, WOC and CSI Subscales*

Instrument	<i>M</i>	<i>SD</i>	$\alpha$
<i>SF-36v2 Subscales</i>			
General health	73.60	24.89	.87
Physical functioning	80.00	26.94	.94
Role limitation – Physical	69.60	36.95	.97
Role limitation – Emotional	68.75	36.93	.97
Social functioning	64.21	38.37	.96
Bodily pain	66.59	32.61	.93
Vitality	56.96	24.46	.82
Mental health	70.00	24.43	.88
<i>Ways Coping Questionnaire Subscales (WOC)</i>			
Confrontive coping	7.75	4.48	.71
Self-controlling	10.96	4.5	.64
Seeking social support	9.93	5.06	.82
Planful problem solving	10.21	4.53	.76
Distancing	7.98	4.46	.71
Accepting responsibility	5.09	3.70	.73
Escape-avoidance	9.66	6.75	.85
Positive reappraisal	11.77	5.67	.81
<i>Coping Strategy Indicator (CSI)</i>			
Seeking social support	23.11	6.26	.91
Problem solving	25.86	6.39	.92
Avoidance	20.89	6.05	.87

It is evident from Table 5 that the Cronbach alpha coefficients of all the subscales of all three the measuring instruments utilised in this study were above 0.70, except for the one subscale (Self-controlling) of the Ways of Coping instrument, in which case  $\alpha$  was 0.64. This indicates that the measuring instruments (SF-36v2, WOC and CSI) used in this study, with the

exception of the subscale about self-controlling of the Ways of Coping instrument, show acceptable levels of internal consistency. However, to be able to include the WOC, it was decided to include the subscale about self-controlling of the WOC in further analyses, as all the remaining WOC subscales meet the requirements for acceptable internal consistency

#### 4.4 HRQOL results

To address the first research question to investigate whether there is a significant difference between the HRQOL levels of the PNES group and the HRQOL levels of the control group, a univariate one-way ANOVA was conducted. The results of the SF-36v2 Health Survey are reported in Table 6 below.

Table 6

*ANOVA results of the SF-36v2 Health Survey for the PNES and Control Groups*

SF-36v2 Subscales (0-100)	PNES		Control		<i>F</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
General health	56.29	23.62	90.91	9.08	41.20	< .01
Physical functioning	65.00	30.59	95.00	8.86	19.52	< .01
Role limitation – Physical	42.90	35.53	96.31	6.30	48.20	< .01
Role limitation – Emotional	43.94	35.28	93.56	16.05	36.06	< .01
Social functioning	35.23	30.04	93.18	18.79	58.86	< .01
Bodily pain	41.48	27.27	91.71	10.62	64.79	< .01
Vitality	41.76	21.16	72.16	17.11	27.44	< .01
Mental health	51.21	20.50	88.79	7.91	64.33	< .01

It is evident from Table 6 that the mean scores of the PNES group were lower than those of the control group in all the SF-36v2 subscales. The univariate one-way ANOVA was used to calculate whether there was a significant difference between the mean scores of the SF-36v2 of the PNES and control groups. The mean scores of the participants with PNES were significantly lower than the mean scores of the control group in all eight of the SF-36v2 subscales ( $p < .01$ ). It is evident from the results in Table 6 that the HRQOL was significantly lower than the HRQOL reported by the healthy control group. Therefore, these results indicate that there is a significant difference between the HRQOL of the PNES group and the HRQOL of the control group, which answers the first research question.

An additional analysis, namely a mixed-model repeated measures ANOVA, was conducted to investigate whether the PNES patients in this study also reported significantly lower levels on the *role limitation – physical* subscale than on the *physical functioning* subscale of the HRQOL than were reported in previous studies (see subsection 2.11.3.2 in the literature review) (Al Marzooqi et al., 2004; Lawton et al., 2008; Testa et al., 2007). It also investigated whether the same trend could be found in the healthy control group of our study. In this analysis, the hypothesis that both groups would show the same trend (in terms of difference between the *role limitation – physical* subscale and the *physical functioning* subscale) was tested by the interaction effect. A significant interaction was found between the differences in the scores of the two groups on the two subscales,  $F(1, 42) = 11.030, p < .01$ ; therefore, the hypothesis could be rejected.

Figure 5 below indicates that the PNES group scored lower than the control group did on both scales. However, for the PNES group, the mean score on the *role limitation – physical* (RP-mk) subscale was significantly lower than the mean score on the *physical functioning* (PF-mk) subscale, indicating a trend not observed in the control group.

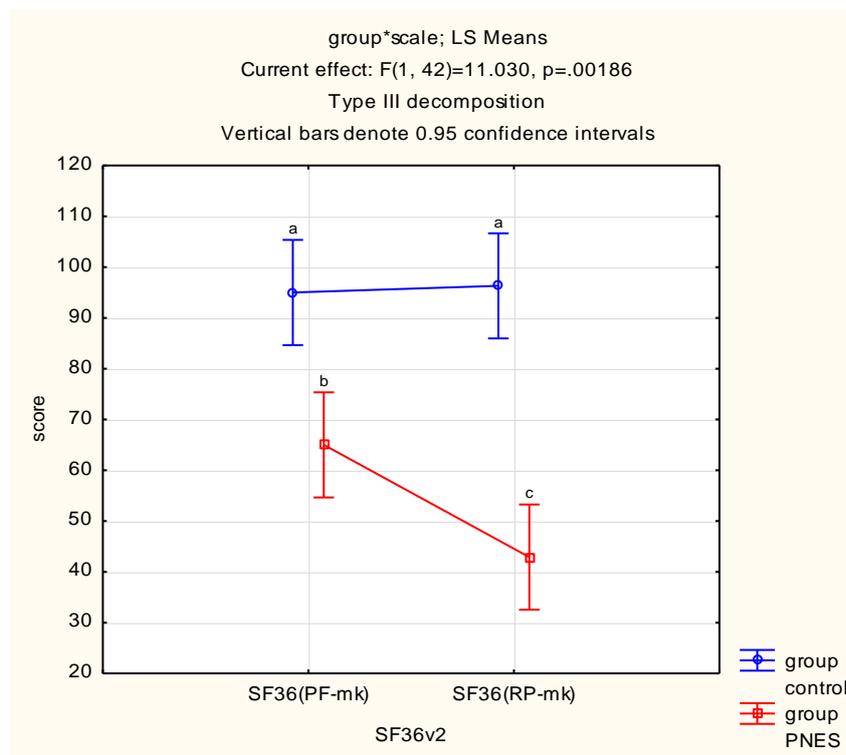


Figure 5. Mean scores for the PNES and control groups on the physical subscales of the SF-36v2 Health Survey.

The results indicated in Figure 5 above support the trend found in previous studies that PNES patients (in contrast with the control group) report significantly lower levels of impairment on the *physical functioning* subscales than on the *role limitation – physical* subscale of the SF-36v2.

## 4.5 Coping results

The two coping instruments (WOC and the CSI) were used to answer the second research question to determine the coping strategies used by participants in the PNES and control groups.

### 4.5.1 WOC results

The results of the univariate one-way ANOVA for the PNES and control groups for the Ways of Coping questionnaire are indicated in Table 7.

Table 7

*ANOVA results of the WOC for the PNES and Control Groups*

Ways of Coping questionnaire subscales	PNES		Control		<i>F</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
<i>Problem-focused</i>						
Confrontive coping	8.41	4.54	7.09	4.43	.95	.33
Self-controlling	11.82	5.46	10.09	3.19	1.64	.21
Seeking social support	10.27	5.48	9.59	4.71	.20	.66
Planful problem solving	9.77	4.70	10.64	4.41	.40	.53
<i>Emotion-focused</i>						
Distancing	9.32	5.01	6.64	3.44	4.28	.05**
Accepting responsibility	5.73	4.23	4.45	3.04	1.31	.26
Escape-avoidance	13.05	6.43	6.27	5.28	14.56	.00***
Positive reappraisal	11.36	6.62	12.18	4.65	.23	.64

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

Table 7 above indicates the results of the univariate one-way ANOVA that was used to calculate whether there was a significant difference in the mean scores of the WOC between the PNES and control groups. The results show a significant difference between the mean scores of the PNES group and the healthy control group on two of the WOC subscales. The PNES group scored significantly higher than the healthy control group (at the 1% significance level) on the *escape-avoidance* subscale,  $F(1, 42) = 14.562$ ,  $p = .00044$ . The

PNES group also scored significantly higher than the healthy control group (at the 5% significance level) on the *distancing* subscale,  $F(1, 42) = 4.2827, p = .04469$ . It is also evident from Table 7 that the PNES group tended to use coping strategies that were more emotion-focused and fewer coping strategies that were problem-focused than the control group did.

#### 4.5.2 CSI results

The results of the univariate one-way ANOVA of the PNES and control groups for the Coping Strategy Indicator are indicated in Table 8 below.

Table 8

*ANOVA results of the CSI for the PNES and Control Groups*

Coping Strategy Indicator (CSI) subscales	PNES		Control		<i>F</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Seeking social support	21.36	6.87	24.86	5.17	3.65	.06*
Problem solving	23.68	7.58	28.05	4.03	5.68	.02**
Avoidance	24.46	5.34	17.32	4.46	23.15	.00***

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

Table 8 indicates the results of the univariate one-way ANOVA that was used to calculate whether there was a significant difference in the mean scores of the CSI between the PNES and control groups. Table 8 indicates a significant difference in mean scores (at the 10% significance level) between the PNES and the control group on the *seeking social support* subscale, with the control group scoring higher than the PNES group,  $F(1,42) = 3.6473, p = .063$ . This shows that the control group made more use of seeking social support as a coping style than the PNES group did. The *problem solving* subscale also showed a significant difference in mean scores (at the 5% significance level) between the two groups, with the control group scoring higher than the PNES group,  $F(1,42) = 5.6839, p = .02172$ . This shows that that the control group was more inclined to use problem solving as a coping style than the PNES group was. Table 8 also indicates a significant difference (at the 1% significance level) between the mean scores of the PNES group and the healthy control group, with the PNES group scoring significantly higher than the healthy control group on the *avoidance* subscale,  $F(1,42) = 23.153, p = .00002$ . This shows that the PNES group tended to use avoidance as a coping style more often than the healthy control group did.

It is evident from the results of both the WOC and the CSI that the PNES group tended to use avoidant coping strategies more often than the healthy control group did.

## 4.6 Correlation analyses

To answer the third research question, which investigated whether there was a relationship between the specific coping strategies of patients with PNES and their HRQOL, Pearson's correlation coefficients were calculated to investigate the nature of the statistical relationship between the HRQOL construct (SF-36v2) and the two coping instruments (WOC and CSI). The total sample (PNES and control group together) was used to investigate whether there was an association between specific coping strategies and HRQOL. To explore whether a relationship existed between HRQOL and specific coping strategies of PNES patients, Pearson's correlation coefficients were calculated for this specific group.

### 4.6.1 Correlation between HRQOL and the WOC

The Pearson correlation coefficient was used to explore the nature of the relationship between the WOC coping strategies and HRQOL for the whole sample ( $N = 44$ ) (refer to Table 9 below).

Table 9

*Pearson's Correlation between HRQOL and WOC (N = 44)*

Ways of Coping questionnaire subscales	<i>r</i>	<i>p</i>
Confrontive coping	-.21	.18
Self-controlling	-.31	.04**
Seeking social support	-.08	.62
Planful problem solving	.07	.65
Distancing	-.32	.03**
Accepting responsibility	-.30	.05*
Escape-avoidance	-.64	.00***
Positive reappraisal	-.05	.76

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

This analysis was conducted to investigate whether there is an association between specific coping strategies and HRQOL. As illustrated in Table 9 above, a significant negative relationship (at the 1% significance level) between *escape-avoidance* coping strategies and HRQOL was indicated by the Pearson correlation coefficient ( $r = -.64, p < .01$ ). The Pearson correlation coefficient indicated a significant negative correlation (at the 5% significance

level) between *self-controlling* ( $r = -.31, p < .05$ ) and *distancing* ( $r = -.32, p < .05$ ) coping strategies and HRQOL. The Pearson correlation coefficient also indicated a negative correlation (at the 10% significance level) between *accepting responsibility* ( $r = -.30, p < .10$ ) and HRQOL. Furthermore (and as illustrated in Table 9 above), the Pearson correlation coefficient indicated that *playful problem solving* is positively correlated with HRQOL, but it did not indicate a significant correlation. The results generally seem to support the general trend in the literature that avoidant coping is associated with a low HRQOL.

#### 4.6.2 Correlation between HRQOL and the CSI

The Pearson correlation coefficient was used to explore the nature of the relationships between the WOC coping strategies and HRQOL. The Pearson correlation coefficients are reported in Table 10.

Table 10

*Pearson's Correlation between HRQOL and the CSI (N = 44)*

Coping Strategy Indicator (CSI)	<i>r</i>	<i>p</i>
Seeking social support	.12	.45
Problem solving	.32	.03**
Avoidance	-.60	.00***

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

This analysis was conducted to investigate whether there was an association between specific coping strategies and HRQOL. As illustrated in Table 10 above, *problem solving* is correlated positively (significant at the 5% significance level) with HRQOL ( $r = .32, p < .05$ ) indicating that the use of problem solving as a coping strategy had a positive effect on the HRQOL of the participants. Furthermore (and as illustrated in Table 10 above), the negative correlation between the *avoidance* coping strategy scale and the HRQOL scale was also significant (at the 1% significance level) ( $r = -.60, p < .01$ ). The results reported in Table 10 support the trend in the literature that avoidant coping strategies are associated with a low HRQOL and that problem-solving coping strategies are associated with a higher HRQOL.

#### 4.6.3 Correlation between HRQOL and the WOC of the PNES group

To explore further whether a relationship existed between the HRQOL and specific coping strategies of PNES patients, Pearson correlation coefficients were calculated (refer to Table 11 below). Only the correlation coefficient between the HRQOL construct and the WOC for

the PNES group was investigated, as the WOC had more coping strategies than the CSI. The researcher realised that, although the research attempted to identify association between HRQOL and specific coping strategies of PNES patients, it had to be done with caution because of the sample size of the PNES group ( $n = 22$ ).

Table 11

*Pearson's Correlation between the HRQOL and WOC for PNES Group*

Ways of Coping questionnaire subscales	<i>r</i>	<i>p</i>
Confrontive coping	-.05	.83
Self-controlling	-.33	.14
Seeking social support	-.07	.80
Planful problem solving	-.12	.60
Distancing	-.18	.43
Accepting responsibility	-.27	.22
Escape-avoidance	-.40	.07*
Positive reappraisal	-.25	.25

\*  $p < .10$

This analysis was conducted to investigate whether there was an associationa relationship between specific coping strategies and the HRQOL of PNES patients. It is evident from Table 11 that the *escape-avoidance* coping strategy correlated significantly at the 10% significance level, with a negative HRQOL for PNES patients. These results indicate that avoidant coping strategies seem to be associated with a low HRQOL in PNES patients.

#### **4.7 Regression Analysis**

A regression analysis was conducted to investigate the extent to which HRQOL (dependent variable) can be explained by coping strategies (independent variable).

##### **4.7.1 WOC coping strategies that functioned as key variables in predicting HRQOL**

Table 12 below illustrates the results of the best subset regression analysis that was conducted to determine which of the eight coping strategies of the WOC predicted HRQOL. The summary of the best subset regression indicated that the subscales *self control*, *seeking social support*, *accepting responsibilities* and *positive reappraisal* had very low frequencies ( $R^2$ ); therefore, they were excluded from the multiple regression analysis.

Table 12

*Multiple Regression of the SF-36v2 Health Survey on the WOC Scale*

Predictor	B	Std. error of B	$\beta$	t-ratio	<i>p</i>
Confrontive coping	.42	.16	2.52	2.70	.01**
Planful problem solving	.18	.12	1.08	1.5	.14
Distancing	-.23	.13	-1.40	-1.81	.08*
Escape-avoidance	-.87	.15	-3.44	-5.88	.00***
$F(4, 39) = 12.45$		$R = .75$	$R^2 = 56\%$	$R^2$ (adjusted) = 52%	$SE = 18.62$

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

This analysis was conducted to investigate the extent to which HRQOL could be explained by coping strategies measured by the WOC scale. As illustrated in Table 12 above, the two emotion-focused coping strategies (*escape-avoidance* and *distancing*) emerged as significant predictors of a low HRQOL. The *escape-avoidance* coping strategy was a significant negative predictor (at the 1% significance level) of HRQOL ( $\beta = -3.44, p < .01$ ). The *distancing* coping strategy was a significant negative predictor (at the 10% significance level) of HRQOL ( $\beta = -1.40, p < .10$ ). The two problem-focused coping strategies (*confrontive coping* and *planful problem solving*) emerged as predictors of a high HRQOL. However, the *confrontive coping* strategy was the only significant positive predictor (at the 5% significance level) of HRQOL ( $\beta = 2.52, p < .05$ ). These results support previous findings that avoidance coping strategies are strongly associated with a low HRQOL. Further, Table 12 illustrated that the four subscales of the WOC scale (*confrontive coping, planful problem solving, distancing* and *escape-avoidance*) together accounted for 56% of the variance in the HRQOL total score of this sample. This result was significant at the 1 % level,  $F(4, 39) = 12.45, p < .00000$ . These results indicate that the coping strategies used by the participants may have a significant effect on their HRQOL.

#### 4.7.2 CSI coping strategies that functioned as key variables in predicting HRQOL

Table 13 below illustrates the results of the multiple regression analysis that were conducted to determine which of the three coping strategies of the CSI predicted HRQOL ( $N = 44$ ).

Table 13

*Multiple Regression of the SF-36v2 Health Survey on the CSI Scale*

Predictor	B	Std. error of B	$\beta$	t-ratio	<i>p</i>	
Seeking social support	-.19	.14	-.79	-1.33	.19	
Problem-solving	.26	.14	1.08	1.89	.07*	
Avoidance	-.60	.13	-2.64	-4.69	.00***	
<hr/>						
$F(3, 40) = 9.7149$		$R = .65$	$R^2 = 42\%$	$R^2$ (adjusted) = 38%	$SE = 21.10$	

\*  $p < .10$       \*\*  $p < .05$       \*\*\*  $p < .01$

This analysis was conducted to investigate the extent to which HRQOL could be explained by the coping strategies measured by the CSI scale. As illustrated in Table 13 above, the *avoidance* coping strategy emerged as a significant negative predictor (at the 1% significance level) of HRQOL ( $\beta = -2.64, p < .01$ ). These results support the general notion found in the literature that avoidance coping strategies are strongly associated with a low HRQOL. The *problem-solving* coping strategy emerged as a significant positive predictor of HRQOL ( $\beta = 1.08, p < .10$ ). These results support previous findings that problem-solving coping strategies are associated with a high HRQOL. Table 13 further illustrated that 42% of the variance in the total HRQOL score of the sample could be significantly explained by the CSI scale. This result was significant at the 1 % level,  $F(3, 40) = 9.7149, p < .00006$ . These results provide more insight into the relationship between coping strategies, which has been identified as a potential risk factor for the development of PNES and HRQOL.

#### 4.8 Conclusion

The results of the study were presented in this chapter. The demographic results and the descriptive statistics of the various measuring instruments were discussed. Next, the results of the univariate one-way ANOVA for the healthy control group and the PNES group on the HRQOL and coping instruments were discussed. Finally, the results of the correlation and regression analyses were presented and discussed.

## Chapter 5 Discussion, recommendations and conclusion

In this chapter, the results of the demographic questionnaire, HRQOL (SF-36v2) and the various coping measurements (WOC and CSI) are discussed and interpreted. Then follows a focus on how the results were able to answer the research questions. Next, the transactional theory on emotion and coping of Lazarus and Folkman (1984) is used to integrate the results of this study and existing literature. This is followed by a conclusion, the significance of the study, limitations and suggestions for future research.

### 5.1 Discussion

#### 5.1.1 PNES Participants

Most of the PNES patients ( $n = 21$ ) were referred by the neurologist at the Epilepsy Unit of the Constantiaberg Medi-Clinic. Only four PNES patients with a confirmed VEEG diagnosis were referred by the Department of Neurology at the Tygerberg Hospital. The main reason for the difference in referrals may be that the Tygerberg Hospital has less VEEG equipment than the Constantiaberg Medi-Clinic. As the use of VEEG is quite expensive, they only use the VEEG at the Tygerberg Hospital (a public hospital) to confirm a PNES diagnosis if other diagnostic techniques have failed to provide sufficient support for the diagnosis.

Previous research on PNES reported low participation rates, high drop-out rates and poor response rates (Jones et al., 2010; LaFrance, Blum, Miller, Ryan, & Keitner, 2007; Reuber, Pukrop, Bauer et al., 2003; Taylor, Cahn-Weiner, & Garcia, 2009). Therefore, the participation rate of 88% (22 out of 25) of the PNES group of this study can be interpreted as satisfactory when compared to previous research.

The majority of the PNES sample of this study consisted of women (77%). This tendency seems to be in line with other studies, as most of the available research shows that PNES is still more commonly (e.g. 80%) observed in women (Bora et al., 2011; Devici et al., 2007; Hill & Gale, 2011; Holmes et al., 2001; Prigatano, & Kirilin, 2009; Strutt et al., 2011a).

The mean age (32.77 years) of the current study also seems to be in line with previous research that indicates PNES mostly occurs between the ages of 20 and 30 years (Devici et al., 2007; Krawetz et al., 2001; Reuber, Pukrop, Bauer et al., 2003; Strutt et al., 2011a). However, the age distribution of this sample was bimodal, where 32% of the sample was between the ages of 10 and 20 years and 27% of the sample was between 40 and 50 years. One of the reasons for this distribution may be that the sample consisted of a combination of adolescents and adults (patients of 14 years and older). Most of the other studies focus either

on children and adolescents (e.g. PNES patients younger than 18 years) or on adults (e.g. PNES patients older than 18 years).

Most of the PNES patients in this study (68%) were Caucasian, and the rest of the sample was coloured (32%). The ethnicity categories were included in this study only as a control measure to determine how closely the distribution of the participants reflects the diverse population of South Africa in general. However, the sample size of this study is too small to make any conclusion about the population distribution of PNES patients in South Africa.

Previous research indicate that sociocultural factors such as poor education (Bora et al., 2011; Dhanaraj et al., 2005) and low socioeconomic status (Deveci et al., 2007) may play a role in the development of PNES. In our study, 32% of the PNES participants were still at school. Only 23% of the PNES group had a tertiary education, whereas the rest (more than 40%) had an education level of grade 12 or lower.

In contrast to Deveci et al. (2007), who indicate that low socioeconomic status may play a role in the development of PNES, most of the PNES participants in our study (82%) viewed themselves as being within the middle or high income bracket. One of the reasons for the relative high socioeconomic status of our PNES group may be that most (84%) of the participants were recruited from a private hospital (the Constantiaberg Medi-Clinic). Therefore, these results should be interpreted with care and not be seen as an indication of the general PNES population in South Africa.

Studies indicate that the average period between seizure manifestation and correct diagnosis is about seven years (Jones et al., 2010; LaFrance, 2008; Reuber & Elger, 2003). However, in this study, only 14% of the PNES participants indicated that it took seven years or more after their first seizure manifestation before they were diagnosed with PNES. Most of the PNES participants (55%) received the correct diagnosis of PNES within one year after their first seizure. For the rest of the participants (31%), it took between one to four years before they received the correct diagnosis. A possible reason for the earlier diagnosis in our study may be that the hospital where most of the patients were recruited (the Constantiaberg Medi-Clinic) has an epilepsy-monitoring unit with all the sufficient equipment to confirm a correct diagnosis of PNES. It may not be the case at other epilepsy units in South Africa. It is also possible that there may be patients in South Africa with a longer period (more than seven years) before a correct diagnosis, as our study did not made provision for patients that were not referred to epilepsy units (i.e. they only saw a general practitioner). Even though our

results indicate a shorter period between seizure manifestation and the diagnosis of PNES than previous studies, almost half of the PNES group (45%) only received the correct diagnosis more than one year after their first seizure.

A third (32%) of the PNES sample was diagnosed with epilepsy the first time. These findings seem to be in keeping with previous research, which suggests that PNES is often misdiagnosed with epilepsy (Bodde et al., 2007; Bora et al., 2011; Trimble, 1986). Benbadis and LaFrance (2010) indicate that a high frequency of seizure (e.g. daily) could be a clinical characteristic of PNES. In line with their findings, 50% of the PNES participants in this study have at least one seizure per day, whereas 36% of the participants have at least one seizure a week and the rest of the participants have one seizure every second week.

Researchers indicate that the misdiagnosis of PNES (Hamilton et al., 2010; Martin et al., 1998) and unemployment (Brown et al., 2011; Duncan et al., 2011) increase the medical burden of PNES on society. In this study, a third of the PNES participants were misdiagnosed with epilepsy, for 45% it took more than a year before they were diagnosed correctly and 40% were unemployed or medically retired when they were diagnosed. The medical burden of PNES in the South African context is still unknown, but given these results, it may be substantial and a research avenue worth investigating.

A third of the PNES participants indicated that they were receiving psychological treatment at the time when they completed the research survey. Psychodynamic therapy was the most common form of psychological treatment that the PNES participants received. This is in line with previous research that indicates that psychodynamic therapy is the most commonly used treatment for PNES (LaFrance & Devinsky, 2002).

Most of the PNES participants (68%) indicated that they would like to be part of a support group, and 32% indicated that they would like more information about PNES. From these results, it seems as if there is a need for PNES patients to feel part of a group. To provide these patients with appropriate support, it may be beneficial if the neurologist/psychiatrist provides the patient with enough information and the contact details of a PNES support group when the diagnosis is communicated to the patient.

### 5.1.2 HRQOL

The findings related to HRQOL give us an indication of how the particular two groups (PNES and control) perceive their health. It also gives us an indication of the domains in which the PNES group experiences the most problems. The results indicate that the PNES group reported significantly lower HRQOL than the healthy control group. Similar findings were reported in previous research that also compared PNES patients with healthy control groups or the general population (Jones et al., 2010; Mercer et al., 2010; Ozenli et al., 2008; Uliaszek et al., 2012). Figure 6 below illustrates the difference between the HRQOL scores for the PNES group and the control group of this study (refer to the solid lines). Lower values indicate a lower HRQOL.

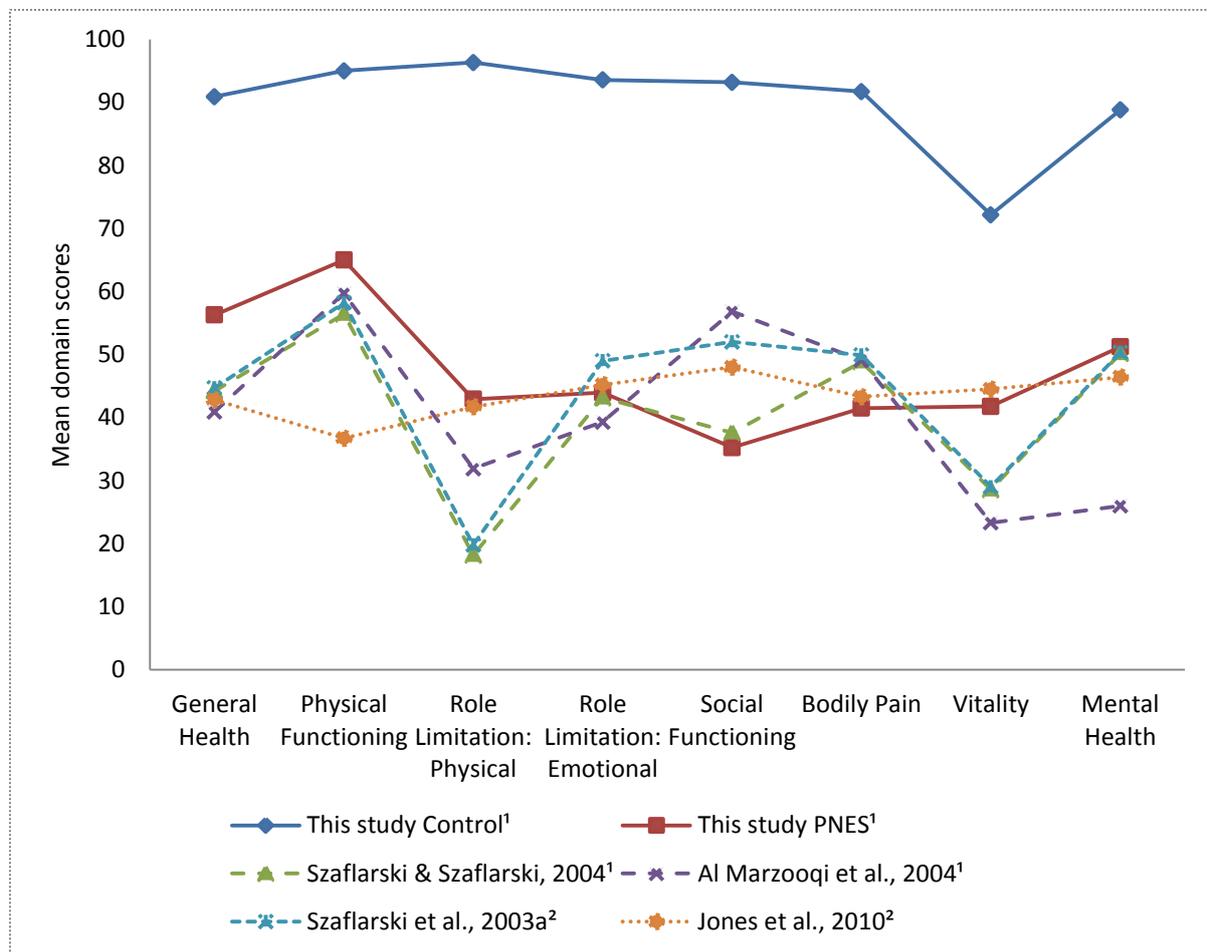


Figure 6. HRQOL scores for this study and trends in HRQOL scores in other PNES studies.

Note: <sup>1</sup> Studies that used the SF-36, <sup>2</sup> Studies that used the QOLIE-89

Figure 6 above also presents the mean scores of PNES patients in other studies on all the HRQOL subscales. Only the PNES studies of which the mean scores for the SF-36 were

available were included in this representation. Of the studies that used the QOLIE-89, only the SF-36 subscales that are also contained in the QOLIE-89 are presented.

In line with previous research (and as illustrated in Figure 6 above), PNES patients in this study reported low HRQOL across all domains (Alsaadi & Marquez, 2005; Al Marzooqi et al., 2004; Szaflarski et al., 2003a; Szaflarski et al., 2003b; Testa et al., 2007). Similarly, in their review study, Mercer et al. (2010) also reported a "general pattern for patients to report lower HRQOL across all domains" (p. 153).

The findings regarding the PNES group in this study are consistent with findings of previously published studies, which show that the lowest scores on HRQOL were on the following subscales; *role limitation: physical*, *role limitation: emotional*, *bodily pain* and *vitality* (Al Marzooqi et al., 2004; Breier et al., 1998; Jones et al., 2010; Lawton et al., 2008; Strutt et al., 2011b; Szaflarski & Szaflarski, 2004; Szaflarski et al., 2003a). These findings indicate that PNES patients experience difficulties with daily activities or work because of their physical health and their emotional problems. These patients also experience severe pain and feel tired most of the time.

A possible reason for these findings may be the high frequency of seizures reported by the PNES group. Significant negative correlations between seizure frequencies and six of the eight subscales of the SF-36 (*role limitation – physical*, *role limitation – emotional*, *bodily pain*, *mental health*, *physical functioning* and *social functioning*,) respectively were found in previous research (Lawton et al., 2008). It is not difficult to see why PNES patients who experience a great number of seizures in a week would experience severe bodily pain and be more disabled in their daily activities or social functioning.

In line with this study, Lawton et al. (2008) and Szaflarski and Szaflarski (2004) in their studies also reported low scores for the PNES group on the *social functioning* subscale. However, other studies reported higher scores on the *social functioning* subscale (Al Marzooqi et al., 2004; Jones et al., 2010; Szaflarski et al., 2003a). The *social functioning* subscale assesses whether emotional problems and the physical health of the participant interfere with his/her social activities (Ware & Sherbourne, 1992). As discussed in the paragraph above, the PNES group in our study indicated low scores on both the physical and emotional role limitation subscales. Therefore, one could argue that it is possible that they would also report frequent interference with their social activities due to physical and emotional problems. In support of this, Strutt et al. (2011b) found that the PNES patients in

their study believed that their low physical, emotional and social functioning was a direct result of their PNES condition.

The PNES group in our study perceived their personal health to be average. Other studies also reported average scores of just above 50% on the general health subscale (Jones et al., 2010; Strutt et al., 2011b). However some studies report a score below 50% on the *general health* subscale, indicating a very low perception of personal health (Al Marzooqi et al., 2004; Breier et al., 1998; Lawton et al., 2008; Szaflarski & Szaflarski, 2004; Szaflarski et al., 2003a).

According to Ware and Sherbourne (1992), a low *mental health* score means that a person is feeling depressed or nervous all the time, whereas a high score would indicate that the person feels calm, happy and peaceful. In line with our study, most of the previous research reported average to low scores on the *mental health* subscale (Jones et al., 2010; Lawton et al., 2008; Strutt et al., 2011b; Szaflarski & Szaflarski, 2004; Szaflarski et al., 2003a). The low HRQOL of PNES patients may be because of psychiatric comorbidity (such as depression), which is often the case with PNES patients (LaFrance & Syc, 2009; Szaflarski & Szaflarski, 2004; Szaflarski et al., 2003a). Unfortunately, the psychiatric conditions of the PNES patients were not evaluated in this study; therefore, the researcher cannot comment on whether psychiatric comorbidity had a greater negative effect on HRQOL in the PNES group than in the healthy control group.

Another possible reason for the low *mental health* score of the PNES patients might be their level of perceived stress. The subjective domain (e.g. psychological well-being) of HRQOL measures how individuals perceive their life to match some internal standard and the likelihood of reaching their goals (Romney & Evans, 1996; WHQOL group, 1995). Research indicates that perceived stress is associated strongly with low mental health (Bovier, Chamot, & Perneger, 2004). Bovier et al. (2004) are of the opinion that "perceived stress results from the assessment of the potential impact of external stressors on the likelihood of reaching one's goal" (p. 169). The PNES group in our study perceived their lives to be significantly more stressful than the healthy control group did. In turn, this suggests that they may be concerned about whether they will reach the goals they have set for themselves, or they may feel that they are not living up to their internal standards.

The objective domain of HRQOL measures the physical functioning of the individual (Romney & Evans, 1996). Our findings support the results of previous research that indicate

that PNES patients tend to report higher levels of impairment on the *role limitation – physical* subscale (problems with work because of physical problems) than on the *physical functioning* subscale (limitation on physical activities) (Al Marzooqi et al., 2004; Lawton et al., 2008; Szaflarski & Szaflarski, 2004; Testa et al., 2007). Previous literature suggests three possible explanations for this: First, it can be that the *physical function* subscale score of the SF-36 does not reflect other aspects of physical dysfunctioning associated with PNES very well, as the questions are based strongly on mobility (e.g. walking a specific distance) (Lawton et al., 2008). It is also possible that, for PNES patients, the impairment of role functioning is not related to actual physical disability but more related to self-imposed restrictions and the avoidance of an activity due to fear of having a seizure (Lawton et al., 2008; Mercer et al., 2010). Third, PNES patients "may in the absence of any physical pathology, exaggerate their poor health status in order to justify their level of disability" (Al Marzooqi et al., 2004, p. 74).

This study has found that the PNES group reported that they generated significantly more avoidance coping strategies in stressful situations than the healthy control group did.

Therefore, I would agree with Lawton et al. (2008) that the low scores on the *role limitation – physical* subscale may be because the PNES patient is avoiding work or an activity, because he/she is afraid that he/she will have a seizure while at work.

On the other hand, having the impairment in role functioning may hold a secondary gain for the PNES patient, if the work or an activity is causing the distress. Therefore, by being physically impaired, the PNES patient can avoid the stressful activity (e.g. the work). In their study, Testa et al. (2012) reported that PNES patients experienced more severe stress related to activities such as work than the control group in their study did. A significant difference was found in our study between the perceptions of the PNES and control groups regarding the stressors in their lives. The PNES group perceived their lives to be significantly more stressful than the control group did. They also struggled more to cope with stressful situations in their lives. Therefore, I would argue that another possible reason for the difference in the results of the two subscales may be avoidance of an activity due to fear of the stressful activity.

Half of the PNES participants in our study have one or more than one seizure a day, while 36% have at least one seizure per week. A third possible explanation may be that the frequency of seizures may be more limiting in work-related activities (reported in the *role limitation – physical* subscale) than in other physical activities (e.g. self-care activities) that contribute to the *physical functioning* subscale.

The significantly low scores on all eight of the health domains highlight the psychological and physical problems PNES patients experience (Al Marzooqi et al., 2004). The results indicate further that treatment targeted at PNES needs to be multifaceted (Jones et al., 2010). Such treatment may involve techniques that could reduce stress and social isolation and improve the patient's awareness of the interaction between his/her emotional and physical functioning (Lawton et al., 2008; Strutt et al., 2011b). In accordance with previous research, the findings of this study emphasize the importance of the use of HRQOL as a secondary measure for therapeutic outcomes (LaFrance & Syc, 2009).

From the discussion above, it can be concluded that PNES has a significant negative impact on the HRQOL of PNES patients. It also suggests that PNES affects every aspect of the patient's life. Furthermore, it indicates that the HRQOL scores of PNES patients in this South African study is comparable with other studies on HRQOL that were done in the USA, UK, Australia and Turkey.

### **5.1.3 Coping**

According to Lazarus (1999), coping can be regarded as an individual's response to manage stressful life conditions. In line with previous research, our study suggests that the PNES participants perceive their lives to be significantly more stressful than the lives of the healthy control group (Frances et al., 1999; Marquez et al., 2004; Testa et al., 2012; Tojtek et al., 2000). The current study also suggests that participants in the PNES group struggle significantly more to cope with life conditions that are stressful than participants in the control group in our study do.

Problem-focused coping and emotion-focused coping are the two main coping strategies an individual will implement in a stressful situation (Lazarus, 1999; Lazarus & Folkman, 1984). According to Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, an individual will use more problem-focused coping strategies if he/she believes that the threatening event can be defeated. However, if the individual believes that the event is unchangeable, he/she will look for possibilities of escape and use more emotion-focused coping strategies. From the WOC, it was clear that the PNES group indicated utilising fewer problem-focused coping strategies than the control group did, even though the scores on the four problem-focused coping strategies (*confrontive coping*, *self-controlling*, *seeking social support* and *planful problem solving*) did not differ significantly from the healthy control group. However, two of the four emotion-focused coping strategies (*distancing* and *escape-*

*avoidance*) on the WOC scale indicated a significant difference between the PNES and control group. The scores of the PNES group were much higher than those of the control group on these scales. Furthermore, on the *problem solving* scale of the CSI, the scores of the control group were significantly higher than those of the PNES group, whereas the scores on the *avoidance* scale were significantly lower than those of the PNES group. Therefore, our results support the findings of previous studies that patients with PNES tend to use more emotion-focused coping strategies than problem-focused coping strategies (Frances et al., 1999; Goldstein et al., 2000; Stanhope et al., 2003; Testa et al., 2012; Zaroff et al., 2004). These results suggest that PNES patients appraise their conditions as unchangeable and out of their control. This is consistent with the tendency of PNES patients to have a more external locus of control (Binzer, 1999; Stone et al., 2004).

In support of Frances et al. (1999), but contrary to the findings of Goldstein et al. (2000), a significant difference ( $p < .05$ ) was found in this study between the PNES and the healthy control group on the *distancing* scores of the WOC scale. The significant difference in the distancing scores indicates that the PNES participants tried to minimize the stressful situation by using cognitive efforts to detach themselves from it. Distancing strategies may be a useful coping technique in certain situations. However, the recurrent use of distancing coping strategies may affect the individual's social functioning, have a negative effect on his/her life and may result in evading to seek the necessary treatment (Frances et al., 1999; Lazarus, 1993; Lazarus & Folkman, 1984).

Another significant difference in the coping strategies of the PNES and control group in our study was on the *escape-avoidance* scale of the WOC and the *avoidance* scale of the CSI. The PNES participants engaged in significantly more ( $p < .01$ ) avoidance coping strategies than the control group in our study. Frances et al. (1999) and Goldstein et al. (2000) both reported a significant difference between the PNES group's scores and the control group's scores on the *escape-avoidance* subscale of the WOC in their studies. Both these studies indicate that the PNES group's score was significantly higher than the control group's score. Thus, our finding and those of Frances et al. (1999) and Goldstein et al. (2000) support the notion that patients with PNES tend to avoid rather than approach stressful situations (Bakvis et al., 2011; Krawitz et al., 2001; Zaroff et al., 2004).

This tendency of avoidance might make them more vulnerable to develop PNES (Baslet, 2011). Research indicates that the use of avoidant coping is associated with increased psychological distress, because patients fail to express their emotions and thereby leave them

unresolved. This can aggravate the disease process and affect the patients' health negatively (De Ridder et al., 2008; Taylor, 2006). The use of avoidant coping strategies may also lead to a failure to seek psychological treatment (Caplan & Plioplys, 2010).

Steinhardt and Dolbier (2007) showed in their study that cognitive behavioural therapy was useful for managing stress and enhancing more effective coping strategies (i.e. lower avoidant and more problem-focused) in adults. Research that focused on the treatment of PNES indicate a reduction in dissociative and avoidance coping strategies utilised by PNES patients after they have received psychological treatment (Bodde et al., 2007; Kuyk et al., 2008; Zaroff et al., 2004). Thus, in support of previous research, we suggest that therapeutic approaches designed to enhance the use of more effective coping strategies by these patients may be appropriate (Caplan & Plioplys, 2010; Testa et al., 2012).

#### **5.1.4 Coping and HRQOL**

Research focussing on illness indicates that coping styles play a major role in HRQOL (Westerhuis et al., 2011; De Ridder et al., 2008; Hesselink et al., 2004). Research further indicates that avoidance coping strategies are related to lower HRQOL (Coelho et al., 2003; Pretorius et al., 2010; Van de Ven et al., 2007). However, no research could be found that studied the association between specific coping strategies and HRQOL of PNES patients. Therefore, I first explored whether relationships exist between specific coping strategies and the HRQOL outcome of our sample.

A significant positive correlation between the *problem solving* scale on the CSI and HRQOL was found in this study. This indicates that the use of problem solving as a coping strategy had a positive effect on the HRQOL of our sample. Previous research suggests that constructive coping styles may have a positive effect on HRQOL (De Ridder et al., 2008; Hesselink et al., 2004). Supporting this statement, our study indicated that the participants in the healthy control group used problem-solving coping strategies much more than the participants in the PNES group did. The HRQOL of the healthy control group was also significantly higher than the HRQOL of the PNES group in our study. Therefore, a positive association may exist between HRQOL and problem-solving coping strategies. The results also indicated that avoidance coping strategies (on both the WOC and CSI scales) correlated significantly with low HRQOL. These results seem to support previous literature in this regard (Coelho et al., 2003; Pretorius et al., 2010; Van de Ven et al., 2007).

To further investigate the extent to which HRQOL (dependent variable) could be explained by coping strategies (independent variable), a regression analysis was conducted on each of the coping scales (WOC and CSI). All the elements of the CSI scale (*seeking social support, problem-solving and avoidance*) and four of the elements on the WOC scale (*confrontive coping, planful problem solving, distancing and escape-avoidance*) respectively accounted for 42% and 56% of the variance in the HRQOL of this sample. The level of HRQOL could be explained significantly by the specific coping strategies used by the participants in our study. The results on the regression analysis indicated further that the avoidance coping strategy emerged as a significant negative predictor of HRQOL.

Furthermore, I explored whether an association exists between specific coping strategies and the HRQOL outcome of the PNES group. The results indicate that, for the PNES participants in this study, avoidance coping strategies correlated significantly with low HRQOL. Research that focused on patients with asthma found that when the patients experienced more disease-related symptoms, they tended to avoid certain situations, which in turn had a negative effect on their HRQOL (Hesselink et al., 2004; Van de Ven et al., 2007). Therefore, it could be speculated that when PNES patients experience more symptoms (such as a seizure), they will avoid situations and triggers that may lead to it. This restricted lifestyle may cause the individual to avoid certain activities, such as social or other extracurricular activities, thereby decreasing their HRQOL.

From the results above, it is evident that PNES has a great effect on an individual's well-being, but often seizure frequency does not explain self-reported HRQOL. Discrepant results of the relationship between seizure frequency and HRQOL in PNES patients have been found (Kuyk et al., 2008; Lawton et al., 2008; Quigg et al., 2002; Reuber et al., 2005). Some studies indicate that the reduction of seizure frequency does not always translate into equal improvement in HRQOL (Quigg et al., 2002; Reuber et al., 2005). A possible reason for this may be the coping strategies utilised by PNES patients. Therefore, it may be possible that, even though the seizure frequency of PNES patients may have declined, they still report a low HRQOL because of their tendency to use avoidance coping strategies. Unfortunately, in this study we did not test whether a correlation between seizure frequency and HRQOL exists for the PNES patients and, therefore, cannot comment on whether seizure frequency had a negative effect on HRQOL in the PNES group. More research is required to understand the interaction between seizure frequency, HRQOL and the coping strategies used by PNES patients.

The novelty of this study is that, for the first time (to my knowledge), an association between the use of avoidance coping strategies and the low HRQOL in patients with PNES was suggested. Although the design does not permit conclusions on causality, these results are important for the treatment of these patients. The development of treatment programmes to encourage PNES patients to adopt more constructive coping strategies may be useful. Research indicates that the HRQOL improved and coping strategies of PNES patients were more adequate after they had received psychological treatment that was also aimed at improving coping skills (Kuyk et al., 2008; LaFrance et al., 2009).

### **5.1.5 Lazarus and Folkman's coping theory**

This study was grounded in Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping. According to Lazarus and Folkman (1984; 1987), cognitive appraisal and coping play a mediating role in the emotional outcome of a threatening event. Negative emotions (such as stress, fear, anger or guilt) that an individual experiences after a stressful encounter can be regarded as the short-term outcome that is generated by the threatening event. Depending on the intensity of the emotional outcome, it may in the long term affect the somatic health of the individual.

According to Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, maladaptive emotion-focused coping can impair health by hindering adaptive health-/illness- related behaviour. A coping process is maladaptive when it leads to poorer physical or emotional health, for example if a person uses only avoidance as a coping strategy to deal with stress. The use of avoidance may lower emotional distress. However, it can prevent the person from addressing the problem realistically and suitably. Thus, the conflict may remain unresolved in the unconscious. In the long run, the associated emotional outcome (e.g. emotional distress) may be channelled through the body and expressed as a physical symptom (e.g. PNES) (Caplan & Plioplys, 2010).

The PNES patients in this study reported utilising coping strategies that are more emotion-focused (such as *escape-avoidance* and *distancing*) than the healthy control group did to deal with stress. When considering Lazarus & Folkman's (1984; 1987) transactional theory on emotion and coping, one could speculate that the use of emotion-focused coping strategies (such as avoidance) of the PNES patients in our study was maladaptive because they still experienced higher levels of stress and struggled significantly more to cope with the stressors of living than the healthy control group did. PNES has been defined as a "physical

manifestation of psychological distress" (Alsaadi & Marquez, 2005, p. 849). Researchers have found that PNES patients often communicate psychological distress in the form of physical complaints (Bewley et al., 2005). According to Owczarek (2003), maladaptive coping mechanisms seem to underlie PNES and help to protect the patient from experiencing other intense negative effects that may arise if unresolved or when irresolvable situations are confronted. Thus, in line with previous research, I argue that the use of maladaptive, emotion-focused coping strategies (more specifically avoidance coping strategies) can affect the somatic health of individuals and make them more vulnerable to the development of PNES (Bakvis et al., 2011; Baslet, 2011; Frances et al., 1999; Lanceman et al., 1993; Zaroff et al., 2004).

Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping also states that "the quality of life and what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (p. 181). If we relate this theory to a person with PNES, we can argue that the person's HRQOL is interwoven with the way he/she perceives the stressors of life and cope with them. For example, for the person, the fear of having a PNES might be perceived as a stressful event. The person will evaluate if something can be done (e.g. if the person has the necessary resources or social skills) to prevent the PNES. If the person feels that he/she is unable to control or deal with it, fear, anxiety and a sense of helplessness is felt and the person will constitute a way to cope with these negative emotions. If there is a poor fit between the coping strategies that are used and the personal agenda (i.e. values, life goals and beliefs) it may increase distress (Folkman et al., 1991). In the long run, the person may experience a negative sense of well-being, because he/she struggles to cope effectively with stress and also to actualize personal goals (Lazarus & Folkman, 1984). Therefore, the way in which the person copes with the threatening event (e.g. PNES) may in the long term affect his/her HRQOL.

In support of Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, the results of the study indicate that coping strategies could account for a significant portion of the variance in the HRQOL total score of the whole group (the PNES and healthy control groups). Problem-focused coping strategies were associated with higher HRQOL, whereas emotional-focused coping strategies (such as avoidance) were associated with lower HRQOL. Furthermore, a significant association was found between avoidance coping strategies used by PNES patients and their low HRQOL. These results suggest that, in the

long term, avoidance coping strategies may also have a negative effect on the social functioning and morale (HRQOL) of PNES patients.

## 5.2 Conclusion

The primary aim of this study was to explore a possible association between coping strategies and the HRQOL of people with PNES. To achieve the aim of this study, the difference between the HRQOL levels of the PNES and healthy control group was determined first. The use of a generic HRQOL measure (the SF-36v2) made it possible to compare the HRQOL results of the PNES group and the healthy control group and also addressed a need identified in previous research (Birbeck & Vickrey, 2003). The results show that the HRQOL of the PNES group was significantly lower than that of the healthy control group in all eight of the health domains of the SF-36v2 health survey. In line with international research (Jones et al., 2010; Mercer et al., 2010; Ozenli et al., 2008; Uliaszek et al., 2012), these results indicate that PNES also has a negative effect on the HRQOL of individuals diagnosed with the disorder in South Africa. It also shows that PNES had a severe negative effect on all emotional, social and physical aspects of the lives of patients participating in our study. It further emphasizes the importance of early diagnosis and submission to appropriate treatment, as this disorder has such an adverse effect on an individual's well-being. Moreover, it supports previous researchers (Lawton et al., 2008; Martin et al., 1998; Mayor et al., 2010) who suggested that HRQOL measures should be used to determine the effectiveness of treatment targeted at patients with PNES.

Second, the differences between the types of coping strategies that PNES participants use in comparison with a healthy control group were determined. The results indicate that PNES patients utilised more emotion-focused coping strategies, whereas the healthy control group implemented more problem-focused coping strategies. A significant difference between the two groups was found on the *escape-avoidance* coping and the *distancing* coping strategy subscales. An *escape-avoidance coping strategy* was the most prominent coping strategy distinction between the PNES and control group. The PNES group perceived their lives to be significantly more stressful and also struggled significantly more to cope with stressful life events than the healthy control group did. These results support the findings in the literature that PNES patients tend to avoid problems (stressful events) they encounter rather than to confront them. Therefore, for PNES patients, the recurrent use of avoidance coping strategies may be considered a maladaptive coping mechanism developed in response to a stressful life event that, in turn, may lead to increased psychological distress. Furthermore, the results, in

support of previous research (Frances et al., 1999; Goldstein et al., 2000; Stanhope et al., 2003; Testa et al., 2012; Zaroff et al., 2004) and building on Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, indicate that maladaptive coping strategies may be a predisposing factor for the development of PNES. The findings of the study highlight the importance that health care professionals must ensure that treatment focuses on improving the coping strategies used by PNES patients.

Third a possible association between HRQOL and coping strategies in patients with PNES was investigated. The results indicate that emotion-focused coping strategies (such as *escape-avoidance* and *distancing*) have a negative effect, whereas problem-focused coping strategies have a positive effect on HRQOL. The results further indicate that coping strategies could significantly explain the level of HRQOL perceived by the participants in our sample. For the PNES group, an association was found between low levels of HRQOL and *escape-avoidance* coping strategies. These results support Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping, which suggests that the way in which individuals cope with stress affects their quality of life.

### **5.3 Significance of study**

When evaluating the results, some strengths of the study should be considered. One of the strengths of this study is that the PNES patients were diagnosed with a VEEG, which is currently the golden standard to confirm the absence of epilepsy. Another is the prospective nature of the study, as much of the available research on PNES is retrospective studies (Bodde et al., 2009; Reuber, 2008). The fact that the control group was comparable to the PNES patients based on age and gender minimized the effect of random factors on the present study (Goldstein et al., 2000). Another strength was the use of a healthy control group instead of patients with ES, as the use of a control group with ES was questioned in previous studies (Mercer et al., 2010). Reuber (2008) also indicates in his review study that "far too many studies have used patients with epilepsy as the only controls" (p. 630).

Moreover, this is the first study of this nature on people with PNES in South Africa. It is unique in that it is the only study that the researcher is aware of that investigated and suggested a relationship between the coping styles and HRQOL of PNES patients.

Research has shown that early diagnosis has a positive effect on the prognosis of PNES (An et al., 2010; Chung et al., 2006). Therefore, it is important that the patient must be diagnosed correctly with PNES as soon as possible. We hope that this study will contribute to raising

more awareness among clinicians in South Africa about the possibility of a PNES diagnosis so that these patients can be diagnosed correctly and start treatment as soon as possible.

This study supports the findings of previous studies that suggest that PNES patients tend to use more maladaptive coping strategies (especially avoidance coping) (Frances et al., 1999; Goldstein et al., 2000, Testa et al., 2012). Research also indicates that PNES patients' coping strategies have become less dissociative or avoidant and more adaptive after treatment (Bodde et al., 2007; Kuyk et al., 2008; Zaroff et al., 2004). In line with previous research (Caplan & Plioplys, 2010), this study also suggests that the treatment of PNES patients should include methods to ensure adaptive rather than maladaptive coping strategies.

#### **5.4 Limitations of study**

A limitation of the present study is the relatively small sample size. Even though the sample size seems to correspond with the low prevalence rate of PNES and sample sizes in previous PNES research that generally vary between 20 and 30 participants (Bodde et al., 2009), I still emphasize that the results of the study need to be interpreted with caution and need replication. The current sample consisted of a convenience sample of PNES patients. Consequently, the findings of the study cannot be generalized validly beyond this particular population.

The fact that the results represent the experience of patients from only two epilepsy centers (both of which are in the Western Cape region of South Africa) may reflect biases of the epilepsy practices involved. However, I would like to note that the PNES patients recruited from the epilepsy unit of the Constantiaberg Medi-Clinic were from across the country, as that unit is the best equipped in South Africa to diagnose PNES. The fact that most of the PNES patients in our study were recruited from a private hospital may also make our results biased, as most South African citizens do not have the necessary medical aid that will enable them to make use of private hospital facilities. Thus, generalizing the results of the current study to individuals from particularly deprived socio-economic backgrounds or with relatively low levels of formal education would be inappropriate. It would be advisable to replicate this study in a randomly selected cross-sectional sample of South African citizens.

Another limitation of the present study is the lack of a clinical control group, which makes it difficult to state the specificity of the effects for the group with PNES and to exclude the possibility that HRQOL was mediated by comorbid psychopathology (e.g. depression).

Psychiatric measures were also not used to assess the potential influence of psychiatric conditions on the self-reported health status (HRQOL) of the participants.

The reliance on the use of self-reported measures to assess coping strategies and perceived health status, may not reflect actual behaviour. However, the SF-36v2 and the coping measurements (WOC and CSI) have been used widely and are regarded as valid and reliable measures. Therefore, accepting these limitations, the results highlight the perceived low HRQOL and the coping strategies used by individuals with PNES.

### **5.5 Suggestions for future research**

This study highlights that, even though the prevalence rate of PNES may be unknown in South Africa, the disorder has a severe effect on the HRQOL of these patients. For this reason, it may be worthwhile to investigate psychological treatment options that can improve the HRQOL of PNES patients.

This study also indicated that an association exists between low HRQOL and avoidance coping in PNES patients. Therefore, further research that investigates the relationship between HRQOL and coping in patients with PNES seems promising for the improvement of treatment of this debilitating disorder. A follow-up study with the same group of PNES participants may be worthwhile to investigate whether their seizure frequency has decreased, their HRQOLs improved and their coping strategies have changed after appropriate treatment.

The results indicate that it takes several years for these individuals to be diagnosed with PNES in South Africa. The results also indicate that many of these patients are unemployed. Therefore, it may be worthwhile to investigate the medical burden of PNES in South Africa. As the incidence rate of PNES is still unknown, it may also be useful to investigate the incidence rate of this disorder at an epilepsy-monitoring unit in South Africa.

The sample size of the study was relatively small; therefore, it may be worthwhile to replicate the study using a bigger sample size to gain additional insight on the coping styles, HRQOL and the relationship between these two constructs.

Previous research indicates that cultural factors are likely to affect the frequency and form of PNES (Martínez-Taboas et al., 2010). The aim of this study was not to focus on the cultural aspects of PNES. However, it was interesting to note that the ethnic distribution of this sample was not very diverse even though South Africa is a culturally diverse country. There

could be numerous reasons for this unequal distribution in our sample. Therefore, it may be worthwhile to investigate the cultural factors that may affect PNES.

Most of the participants in our study indicated that they would like to be part of a support group. Research indicates that PNES patients reported that being part of a group made them feel less isolated (Prigatano et al., 2002). Therefore, it may be worthwhile to conduct a study where a support group is part of the treatment plan to determine the treatment outcome and effect on the HRQOL of PNES patients.

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## Appendices

### Appendix 1: Demographic questionnaire for PNES participant

#### COPING STYLES AND QUALITY OF LIFE IN PATIENTS WITH PSYCHOGENIC NONEPILEPTIC SEIZURES: A SOUTH AFRICAN PERSPECTIVE

**Instructions:**

- Please answer all the questions
- It will take approximately 45 minutes to complete the survey
- It is very important that you **follow all the instructions carefully** and answer the questions as honestly as possible.
- Your participation is strictly confidential and your answers will remain anonymous.

**Demographic information:**

Initials: \_\_\_\_\_ Date: \_\_\_\_\_

1.) Gender:  Male  Female

2.) Birth date: (DD/MM/JJJJ) \_\_\_\_\_

3.) Age: \_\_\_\_\_

4.) To what population group do you belong?

- Black
- Brown/Coloured
- White
- Indian
- Other (please specify) \_\_\_\_\_

5.) What language do you speak at home?

- Afrikaans
- English
- Xhosa
- Other (please specify) \_\_\_\_\_

6.) What is your marital status?

Single	
Married	
Divorced	
Widow / widower	

7.) What is your highest education level?

Before grade 12	
Grade 12	
Tertiary Diploma	
Degree at university	
Master degree	
PhD	
Other	

8.) Where do you live (town/city)? \_\_\_\_\_

9.) What is your employment status?

Unemployed	
Full-time employed	
Part-time employed	
Homemaker	
Medically retired	
Retired	
Student	

10.) If employed, what type of work do you do? \_\_\_\_\_

11.) In what income group does your household fall in?

- Low income
- Middle income
- High income

12.) Do you have any disabilities?  Yes  No

13.) Do you receive a disability grant?  Yes  No

14.) Have you been diagnosed with a psychiatric disorder within the past year?

- Yes  No

15.) Have you had any kind of seizure before?  Yes  No

16.) If yes, how old were you when you had your first seizure/ episode? \_\_\_\_\_

17.) Have you been diagnosed with epilepsy before? \_\_\_\_\_

18.) How long did it take before you were diagnosed with PNES?

Less than 1 year	
1 year	
1 – 2 years	
2 – 3 years	
3 - 4 years	
4 – 5 years	
5 – 6 years	
6 – 7 years	
More than 7 years	

19.) How old were you when you were first diagnosed with PNES? \_\_\_\_\_

20.) How often do you have seizures?

More than 1 a day	
1 every day	
Once a week	
More than once a week	
Every 2 <sup>nd</sup> week	
Once a month	
Every 2 <sup>nd</sup> month	
Half yearly	
Once a year	

21.) Do you perceive your life as stressful?  Yes  No

22.) Do you sometimes struggle to cope with stressful situations?  Yes  No

23.) Are you currently receiving any treatment?  Yes  No

24.) If yes, what type of treatment are you receiving? \_\_\_\_\_

25.) Would you like to be part of a support group?  Yes  No

26.) If yes, would you like to receive your support individually or in a group?

Individually  Group

28.) What type of support would you like?

More information	
Telephonic	
Website	
Talk to someone who had PNES	

## Appendix 2: Demographic questionnaire for Healthy control group participant

### COPING STYLES AND QUALITY OF LIFE IN PATIENTS WITH PSYCHOGENIC NONEPILEPTIC SEIZURES: A SOUTH AFRICAN PERSPECTIVE

#### Instructions:

- Please answer all the questions
- It will take approximately 45 minutes to complete the survey
- It is very important that you **follow all the instructions carefully** and answer the questions as honestly as possible.
- Your participation is strictly confidential and your answers will remain anonymous.

#### Demographic information:

Initials: \_\_\_\_\_ Date: \_\_\_\_\_

1.) Gender:  Male  Female

2.) Birth date: (DD/MM/JJJJ) \_\_\_\_\_

3.) Age: \_\_\_\_\_

4.) To what population group do you belong?

- Black
- Brown/Coloured
- White
- Indian
- Other (please specify) \_\_\_\_\_

5.) What language do you speak at home?

- Afrikaans
- English
- Xhosa
- Other (please specify) \_\_\_\_\_

6.) What is your marital status?

Single	
Married	
Divorced	
Widow / widower	

7.) What is your highest education level?

Before grade 12	
Grade 12	
Tertiary Diploma	
Degree at university	
Master degree	
PhD	
Other	

8.) Where do you live (town/city)? \_\_\_\_\_

9.) What is your employment status?

Unemployed	
Full-time employed	
Part-time employed	
Homemaker	
Medically retired	
Retired	
Student	

10.) If employed, what type of work do you do? \_\_\_\_\_

11.) In what income group does your household fall in?

- Low income
- Middle income
- High income

12.) Do you have any disabilities?  Yes  No

13.) Do you receive a disability grant?  Yes  No

14.) Have you been diagnosed with a psychiatric disorder within the past year?

- Yes  No

15.) Have you had any kind of seizure before?  Yes  No

16.) If yes, how old were you when you had your first seizure/ episode? \_\_\_\_\_

17.) Have you been diagnosed with epilepsy before? \_\_\_\_\_

18.) Do you perceive your life as stressful?  Yes  No

19.) Do you sometimes struggle to cope with stressful situations?  Yes  No

## Your Health and Well-Being

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**This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!**

**For each of the following questions, please mark an  in the one box that best describes your answer.**

**1. In general, would you say your health is:**

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**2. Compared to one year ago, how would you rate your health in general now?**

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

Yes, limited a lot	Yes, limited a little	No, not limited at all
▼	▼	▼

- a Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports .....  1 .....  2 .....  3
- b Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.....  1 .....  2 .....  3
- c Lifting or carrying groceries .....  1 .....  2 .....  3
- d Climbing several flights of stairs .....  1 .....  2 .....  3
- e Climbing one flight of stairs .....  1 .....  2 .....  3
- f Bending, kneeling, or stooping .....  1 .....  2 .....  3
- g Walking more than a mile.....  1 .....  2 .....  3
- h Walking several hundred yards .....  1 .....  2 .....  3
- i Walking one hundred yards .....  1 .....  2 .....  3
- j Bathing or dressing yourself .....  1 .....  2 .....  3

**4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a	Cut down on the <u>amount of time</u> you spent on work or other activities.....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b	<u>Accomplished less</u> than you would like .....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c	Were limited in the <u>kind</u> of work or other activities .....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d	Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) .....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a	Cut down on the <u>amount of time</u> you spent on work or other activities.....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b	<u>Accomplished less</u> than you would like .....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c	Did work or other activities <u>less carefully than usual</u> .....				
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
	▼	▼	▼	▼	▼	
a	Did you feel full of life? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
b	Have you been very nervous? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
c	Have you felt so down in the dumps that nothing could cheer you up? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
d	Have you felt calm and peaceful? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
e	Did you have a lot of energy? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
f	Have you felt downhearted and depressed? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
g	Did you feel worn out? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
h	Have you been happy? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
i	Did you feel tired? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5

**10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**11. How TRUE or FALSE is each of the following statements for you?**

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
▼	▼	▼	▼	▼

- a I seem to get sick a little easier than other people .....  1 .....  2 .....  3 .....  4 .....  5
- b I am as healthy as anybody I know .....  1 .....  2 .....  3 .....  4 .....  5
- c I expect my health to get worse .....  1 .....  2 .....  3 .....  4 .....  5
- d My health is excellent .....  1 .....  2 .....  3 .....  4 .....  5

***Thank you for completing these questions!***

## **Appendix 4 : Ways of Coping Questionnaire**

### **Ways of Coping Questionnaire**

#### **Instructions**

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the past week.

By 'stressful' we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statement, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate, by circling 0, 1, 2, or 3, to what extent you used in the situation. Key:

0 = Does not apply or not used

1 = Used somewhat

2 = Used quite a bit

3 = Used a great deal

**Please try to respond to every question**

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I just concentrated on what I had to do next – the next step.....0 1 2 3
2. I tried to analyse the problem in order to understand it better.....0 1 2 3
3. I turned to work or another activity to take my mind off things.....0 1 2 3
4. I felt that time would have made a difference – the only thing was to  
wait .....0 1 2 3
5. I bargained or compromised to get something positive from the  
situation.....0 1 2 3
6. I did something that I didn't think would work, but at least I was doing  
something.....0 1 2 3
7. I tried to get the person responsible to change his or her mind.....0 1 2 3
8. I talked to someone to find out more about the situation.....0 1 2 3
9. I criticized or lectured myself.....0 1 2 3
10. I tried not to burn my bridges, but leave things open somewhat.....0 1 2 3
11. I hope for a miracle.....0 1 2 3
12. I went along with fate; sometimes I just have bad luck.....0 1 2 3
13. I went on as if nothing had happened.....0 1 2 3
14. I tried to keep my feelings to myself.....0 1 2 3
15. I looked for the silver lining, so to speak; I tried to look on the bright  
side of things.....0 1 2 3
16. I slept more than usual.....0 1 2 3
17. I expressed anger to the person (s) who caused the problem.....0 1 2 3
18. I accepted sympathy and understanding from someone.....0 1 2 3
19. I told myself things that helped me feel better.....0 1 2 3

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

20. I was inspired to do something creative about the problem.....0 1 2 3
21. I tried to forget the whole thing.....0 1 2 3
22. I got professional help.....0 1 2 3
23. I changed or grew as a person.....0 1 2 3
24. I waited to see what would happen before doing anything.....0 1 2 3
25. I apologized or did something to make up.....0 1 2 3
26. I made a plan of action and followed it.....0 1 2 3
27. I accepted the next best thing to what I wanted.....0 1 2 3
28. I let my feelings out somehow.....0 1 2 3
29. I realized that I had brought the problem on myself.....0 1 2 3
30. I came out of the experience better than when I went in.....0 1 2 3
31. I talked to someone who could do something concrete about the  
 problem.....0 1 2 3
32. I tried to get away from it for a while by resting or taking a vacation.....0 1 2 3
33. I tried to make myself feel better by eating, drinking, smoking, using  
 drugs, or medication, etc.....0 1 2 3
34. I took a big chance or did something very risky to solve the problem.....0 1 2 3
35. I tried not to act too hastily or follow my first hunch.....0 1 2 3
36. I found new faith.....0 1 2 3
37. I maintained my pride and kept a stiff upper lip.....0 1 2 3
38. I rediscovered what is important in life.....0 1 2 3
39. I changed something so things would turn out all right.....0 1 2 3
40. I generally avoided being with people.....0 1 2 3

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

41. I didn't let it get to me; I refused to think too much about it.....0 1 2 3
42. I asked advice from a relative or friend I respected.....0 1 2 3
43. I kept other from knowing how bad things were.....0 1 2 3
44. I made light of the situation; I refused to get too serious about it.....0 1 2 3
45. I talked to someone about how I was feeling.....0 1 2 3
46. I stood my ground and fought for what I wanted.....0 1 2 3
47. I took it out on other people.....0 1 2 3
48. I drew on my past experiences; I was in a similar situation before.....0 1 2 3
49. I knew what had to be done, so I doubled my efforts to make things  
work.....0 1 2 3
50. I refused to believe that it had happened.....0 1 2 3
51. I promised myself that things would be different next time.....0 1 2 3
52. I came up with a couple of different solutions to the problem.....0 1 2 3
53. I accepted the situation, since nothing could be done.....0 1 2 3
54. I tried to keep my feeling about the problem from interfering with other  
things.....0 1 2 3
55. I wished that I could change what had happened or how I felt.....0 1 2 3
56. I changed something about myself.....0 1 2 3
57. I daydreamed or imagined a better time or place than the one I was in...0 1 2 3
58. I wished that the situation would go away or somehow be over with.....0 1 2 3
59. I had fantasies or wishes about how things might turn out.....0 1 2 3
60. I prayed.....0 1 2 3
61. I prepared myself for the worst.....0 1 2 3

*0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal*

62. I went over in my mind what I would say or do.....**0 1 2 3**
63. I thought about how a person I admire would handle this situation and  
used that as a model.....**0 1 2 3**
64. I tried to see things from the other person's point of view.....**0 1 2 3**
65. I reminded myself how much worse things could be.....**0 1 2 3**
66. I jogged or exercised.....**0 1 2 3**

## Appendix 5: Coping Strategy Indicator

### COPING STRATEGY INDICATOR

We are interested in how people cope with the problems and troubles in their lives. Listed below are several possible ways of coping. We would like you to indicate to what extent you, yourself, used each of these coping methods. All of your responses will remain anonymous.

Try to think of one problem you have encountered in the last six months or so. This should be a problem that was important to you, and that caused you to worry (anything from the loss of a loved one to a traffic citation, but one that was important to you).

Please describe this problem in a few words (remember, your answer will be kept anonymous):

.....  
.....  
.....

With this problem in mind, indicate how you coped by checking the appropriate box for each coping behaviour listed on the following pages. Answer each and every question even though some may sound similar.

Did you remember to write down your problem? If not, please do so before going on.

**Keeping that stressful event in mind, indicate to what extent you...**

1. Let your feelings out to a friend?  **A lot**  **A little**  **Not at all**
2. Rearranged things around you so that your problem had the best chance of being resolved?  **A lot**  **A little**  **Not at all**
3. Brainstormed all possible solutions before deciding what to do?  **A lot**  **A little**  **Not at all**
4. Tried to distract yourself from the problem?  **A lot**  **A little**  **Not at all**
5. Accepted sympathy and understanding from someone?  **A lot**  **A little**  **Not at all**
6. Did all you could to keep others from seeing how bad things really were?  **A lot**  **A little**  **Not at all**
7. Talked to people about the situation because talking about it helped you to feel better?  **A lot**  **A little**  **Not at all**
8. Set some goals for yourself to deal with the situation?  **A lot**  **A little**  **Not at all**
9. Weighed your options very carefully?  **A lot**  **A little**  **Not at all**
10. Daydreamed about better times?  **A lot**  **A little**  **Not at all**
11. Tried different ways to solve the problem until you found one that worked?  **A lot**  **A little**  **Not at all**
12. Confined your fears and worries to a friend or relative?  **A lot**  **A little**  **Not at all**
13. Spent more time than usual alone?  **A lot**  **A little**  **Not at all**
14. Told people about the situation because just talking about it helped you to come up with solutions?  **A lot**  **A little**  **Not at all**
15. Thought about what needed to be done to straighten things out?  **A lot**  **A little**  **Not at all**
16. Turned your full attention to solving the problem?  **A lot**  **A little**  **Not at all**
17. Formed a plan of action in your mind?  **A lot**  **A little**  **Not at all**
18. Watched television more than usual?  **A lot**  **A little**  **Not at all**
19. Went to someone (friend or professional) in order to help you feel better?  **A lot**  **A little**  **Not at all**

20. Stood firm and fought for what you wanted in the situation?  **A lot**  **A little**  **Not at all**
21. Avoided being with people in general?  **A lot**  **A little**  **Not at all**
22. Buried yourself in a hobby or sports activity to avoid the problem?  **A lot**  **A little**  **Not at all**
23. Went to friend to help you feel better about the problem?  **A lot**  **A little**  **Not at all**
24. Went to a friend for advice on how to change the situation?  **A lot**  **A little**  **Not at all**
25. Accepted sympathy and understanding from friends who had the same problem?  **A lot**  **A little**  **Not at all**
26. Slept more than usual?  **A lot**  **A little**  **Not at all**
27. Fantasized about how things could have been different?  **A lot**  **A little**  **Not at all**
28. Identified with characters in novels or movies?  **A lot**  **A little**  **Not at all**
29. Tried to solve the problem?  **A lot**  **A little**  **Not at all**
30. Wished that people would just leave you alone?  **A lot**  **A little**  **Not at all**
31. Accepted help from a friend or relative?  **A lot**  **A little**  **Not at all**
32. Sought reassurance from those who know you best?  **A lot**  **A little**  **Not at all**
33. Tried to carefully plan a course of action rather than acting on impulse?  **A lot**  **A little**  **Not at all**

**You may STOP here.**

**Thank you for your cooperation!**

## **Appendix 6: Informed consent form for PNES patient older than 18 years**

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 021 – 808 9019

You are invited 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 feel free to ask the researcher 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. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

The study will mainly be conducted at the Epilepsy Unit in Constantiaberg Medi-Clinic and Tygerberg Hospital. We will be recruiting at least 50 participants for this study. The purpose of this study is to investigate whether there is an association between specific coping styles and the quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by psychological

distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree to participate and are suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your participation, we will proceed with the study. We will ask you to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information about you and your journey before you were diagnosed with PNES.
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measure both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take you longer than 45 minutes, but you can take as long as you need. If you are still in the hospital you can complete it in your hospital room or otherwise at home.

### **Why have you been invited to participate?**

You have been invited to participate in this study, because you have recently been diagnosed with PNES or you are the same age and gender of someone who have recently been diagnosed with PNES. You are 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to complete the survey as honestly as possible and to the best of your ability.

### **Will you benefit from taking part in this research?**

There may be no direct benefits to you for participating in this study. However, you will have the opportunity to account for your experience of PNES thus far. You will also have the opportunity to reflect on your quality of life and your coping strategies.

The benefit of the study is that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa. This information will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involved in taking part in the study, but if you experience any discomfort during the research you may withdraw.

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

If you decide not to take part in the study there will be no negative consequences.

**Who will have access to your medical records?**

Your participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with you, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

No, you will not be paid to take part in the study and there will be no costs involved for you, if you do participate.

**Is there anything else that you should know or do?**

- You can contact Dr Butler at tel. 021 – 797 2099 if you have any further questions or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

## Declaration by participant

By signing below, I ..... agree to take part in a research study entitled: Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language that I am fluent in and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately 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 will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by investigator**

I *Gretha Cronje* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....

**Signature of investigator**

.....

**Signature of witness**

## **Appendix 7: Informed consent form for parents of PNES patients younger than 18 years**

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 021- 808 9019

Your child (*or ward, if applicable*) is invited 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 feel free to ask the researcher 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 your child could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to withdraw him/her from the study at any point, even if you do initially agree to let him/her take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

The study will mainly be conducted at the Epilepsy Unit in Constantiaberg Medi-Clinic and Tygerberg Hospital. We will be recruiting at least 50 participants for this study. The purpose of this study is investigate whether there is an association between specific coping styles and the quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by psychological

distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree that your child may participate and your child is suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your child's participation, we will proceed with the study. We will ask your child to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information about your child and the journey before your child before he/she have been diagnosed with PNES.
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measure both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take your child longer than 45 minutes, but your child can take as long as he/she need. If your child are still in the hospital he/she can complete it in your hospital room or otherwise at home.

### **Why has your child been invited to participate?**

Your child has been invited to participate in this study, because he/she have recently been diagnosed with PNES. Your child is 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to ensure that your child complete the survey as honestly as possible and to the best of his/her ability.

### **Will your child benefit from taking part in this research?**

There may be no direct benefits to your child for participating in this study. Your child will, however, have the opportunity to share his/her experience of PNES. He or she

will also have the opportunity to reflect on their quality of life and their coping strategies. The benefit of the study is that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa. This information will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involved in taking part in the study, but if your child experience any discomfort during the research he or she may withdraw.

**If you do not agree to allow your child to take part, what alternatives does your child have?**

If you decide that your child may not to take part in the study this will not interfere with the normal treatment offered at the hospital.

**Who will have access to your child's medical records?**

Your child's participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with your child, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

You or your child will not be paid to take part in the study. There will be no costs involved for you if your child does take part.

**Is there anything else that you should know or do?**

- You can contact Dr Butler at tel. 021-797 9022 if you have any further questions or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your child's researcher.

- You will receive a copy of this information and consent form for your own records.

### Declaration by parent/legal guardian

By signing below, I (name of parent/legal guardian) ..... agree to allow my child (name of child) ..... who is ..... years old, to take part in a research study entitled: Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

### I declare that:

- I have read or had read to me this information and consent form and that it is written in a language that I am fluent in and comfortable with.
- If my child is older than 7 years, he/she must agree to take part in the study and his/her ASSENT must be recorded on this form.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to let my child take part.
- I may choose to withdraw my child from the study at any time and my child will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished, if the researcher feels it is in my child's best interests, or if my child does not follow the study plan as agreed to.

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

.....  
**Signature of parent/legal guardian**

.....  
**Signature of witness**

## Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above.
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of investigator**

## Appendix 8: Child assent form for PNES patient

### **PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 021 – 808 9019

You are invited 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 feel free to ask the researcher 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. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

The study will mainly be conducted at the Epilepsy Unit in Constantiaberg Medi-Clinic and Tygerberg Hospital. We will be recruiting at least 50 participants for this study. The purpose of this study is to investigate whether there is an association between specific coping styles and the quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by psychological distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree to participate and are suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your participation, we will proceed with the study. We will ask you to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information about you and your journey before you were diagnosed with PNES.
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measure both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take you longer than 45 minutes, but you can take as long as you need. If you are still in the hospital you can complete it in your hospital room or otherwise at home.

### **Why have you been invited to participate?**

You have been invited to participate in this study, because you have recently been diagnosed with PNES or you are the same age and gender of someone who have recently been diagnosed with PNES. You are 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to complete the survey as honestly as possible and to the best of your ability.

### **Will you benefit from taking part in this research?**

There may be no direct benefits to you for participating in this study. However, you will have the opportunity to account for your experience of PNES thus far. You will also have the opportunity to reflect on your quality of life and your coping strategies. The benefit of the study is that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa. This information

will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involved in taking part in the study, but if you experience any discomfort during the research you may withdraw.

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

If you decide not to take part in the study there will be no negative consequences.

**Who will have access to your medical records?**

Your participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with you, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

No, you will not be paid to take part in the study and there will be no costs involved for you, if you do participate.

**Is there anything else that you should know or do?**

- You can contact Dr Butler at tel. 021 – 797 2099 if you have any further questions or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

## Declaration by participant

By signing below, I ..... agree to take part in a research study entitled: Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language that I am fluent in and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately 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 will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by investigator**

I *Gretha Cronje* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of investigator**

.....  
**Signature of witness**

## **Appendix 9: Informed consent form for healthy control participant older than 18 years**

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, University of Stellenbosch

**CONTACT NUMBER:** 021 – 808 9019

You are invited 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 feel free to ask the researcher 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. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

The study will mainly be conducted at the University of Stellenbosch and a private practice of a general practitioner in Wellington. We will be recruiting at least 50 participants for this study. The purpose of this study is to investigate whether there is an association between specific coping styles and the quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by

psychological distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree to participate and are suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your participation, we will proceed with the study. We will ask you to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information of you.
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measures both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take you longer than 45 minutes, but you can take as long as you need.

### **Why have you been invited to participate?**

You have been invited to participate in this study, because you are the same age and gender of someone who have recently been diagnosed with PNES. You are 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to complete the survey as honestly as possible and to the best of your ability.

### **Will you benefit from taking part in this research?**

There may be no direct benefits to you for participating in this study. However you will have the opportunity to reflect on your quality of life and your coping strategies. The benefit of the study is that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa. This information will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involved in taking part in the study, but if you experience any discomfort during the research you may withdraw.

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

If you decide not to take part in the study there will be no negative consequences.

**Who will have access to your records?**

Your participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with you, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

You will not be paid to take part in the study and there will be no costs involved for you, if you do participate.

**Is there anything else that you should know or do?**

- You can contact Gretha Cronje at 021 – 808 9019 if you have any further questions or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

## Declaration by participant

By signing below, I ..... agree to take part in a research study entitled: Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language that I am fluent in and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately 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 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 as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of participant**

.....  
**Signature of witness**

## Declaration by investigator

I *Gretha Cronje* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of investigator**

.....  
**Signature of witness**

**Appendix 10: Informed consent form for parent of healthy control participant younger than 18 years**

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR USE BY PARENTS/LEGAL GUARDIANS**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, Stellenbosch University

**CONTACT NUMBER:** 021- 808 9019

Your child (*or ward, if applicable*) is invited 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 feel free to ask the researcher 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 your child could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to withdraw him/her from the study at any point, even if you do initially agree to let him/her take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

The study will mainly be conducted at the University of Stellenbosch and a private practice of a general practitioner in Wellington. We will be recruiting at least 50 participants for this study. The purpose of this study is to see if there is an association between specific coping styles and quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by

psychological distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree that your child may participate and your child is suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your child's participation, we will proceed with the study. We will ask your child to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information of your child .
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measures both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take your child longer than 45 minutes, but your child can take as long as you need.

### **Why has your child been invited to participate?**

Your child has been invited to participate in this study, because he/she is the same age and gender of someone who have recently been diagnosed with PNES. Your child is 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to ensure that your child complete the survey as honestly as possible and to the best of his/her ability.

### **Will your child benefit from taking part in this research?**

There may be no direct benefits to your child for participating in this study. Your child will have the opportunity to reflect on his/her quality of life and your coping strategies. The benefit of the study will be that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa.

This information will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involve in taking part in the study, but if your child experience any discomfort during the research he/she may withdraw.

**If you do not agree to allow your child to take part, what alternatives does your child have?**

If you decide that your child may not to take part in the study this will not affect your child negatively.

**Who will have access to your child's medical records?**

Your child's participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with your child, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

You or your child will not be paid to take part in the study. There will be no costs involved for you if your child does take part.

**Is there anything else that you should know or do?**

- You can contact Gretha Cronje at 021-808 9019 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your child's researcher.
- You will receive a copy of this information and consent form for your own records.

### Declaration by parent/legal guardian

By signing below, I (*name of parent/legal guardian*)  
..... agree to allow my child (*name of child*)  
..... who is ..... years old, to take part in a research  
study entitled: Coping Styles and Quality of life in patients with Psychogenic  
nonepileptic seizures (PNES): a South African perspective.

#### I declare that:

- I have read or had read to me this information and consent form and that it is written in a language with which I am fluent and comfortable.
- If my child is older than 7 years, he/she must agree to take part in the study and his/her ASSENT must be recorded on this form.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to let my child take part.
- I may choose to withdraw my child from the study at any time and my child will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished if the study doctor or researcher feels it is in my child's best interests, or if my child does not follow the study plan as agreed to.

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

.....  
**Signature of parent/legal guardian**

.....  
**Signature of witness**

## Declaration by investigator

I *Gretha Cronje* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understand all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of investigator**

## Appendix 11: Child assent form for healthy participant

### **PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Gretha Cronje

**ADDRESS:** Department of Psychology, University of Stellenbosch

**CONTACT NUMBER:** 021 – 808 9019

You are invited 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 feel free to ask the researcher 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. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### **What is this research study all about?**

The study will mainly be conducted at the University of Stellenbosch and a private practice of a general practitioner in Wellington. We will be recruiting at least 50 participants for this study. The purpose of this study is to investigate whether there is an association between specific coping styles and the quality of life of patients with PNES. PNES are episodes that seem like epileptic seizures, but are caused by psychological distress. People who suffer from PNES often report their quality of life to be low and use specific coping styles when dealing with a stressful situation.

If you agree to participate and are suitable for our study we will invite you to go through this information and consent form to ensure that you understand what the study entails. Once we have answered any questions that you may have and you have provided written consent (permission) for your participation, we will proceed with the study. We will ask you to complete a survey that consists of the following;

1. A demographic questionnaire to obtain background information of you.
2. The health related quality of life questionnaire SF-36 which consists of 36-items that measures both physical and psychological health.
3. The Ways of coping questionnaire (WAYS) which measures eight different coping strategies and consists of 66 items.
4. The Coping strategy indicator (CSI) that is a 33-item scale designed to measure three coping strategies.

The completion of the survey should not take you longer than 45 minutes, but you can take as long as you need.

### **Why have you been invited to participate?**

You have been invited to participate in this study, because you are the same age and gender of someone who have recently been diagnosed with PNES. You are 14 years or older and also able to read and write in English or Afrikaans.

### **What will your responsibilities be?**

Your responsibilities will be to complete the survey as honestly as possible and to the best of your ability.

### **Will you benefit from taking part in this research?**

There may be no direct benefits to you for participating in this study. However you will have the opportunity to reflect on your quality of life and your coping strategies. The benefit of the study is that it will provide information on the quality of life and coping strategies of people diagnosed with PNES in South-Africa. This information will hopefully help us to gain a better understanding of PNES patients. This may lead to better treatment techniques.

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

There are no risks involved in taking part in the study, but if you experience any discomfort during the research you may withdraw.

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

If you decide not to take part in the study there will be no negative consequences.

**Who will have access to your records?**

Your participation is regarded as strictly confidential. Any information obtained through the conducting of the research and that can be associated with you, will be kept confidential and will only be made available with your permission or as is required by law. The results of the study may be published in professional literature. Confidentiality will, however, be maintained by anonymous completion of the survey.

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

You will not be paid to take part in the study and there will be no costs involved for you, if you do participate.

**Is there anything else that you should know or do?**

- You can contact Gretha Cronje at 021 – 808 9019 if you have any further questions or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

### Declaration by participant

By signing below, I ..... agree to take part in a research study entitled: Coping Styles and Quality of life in patients with Psychogenic nonepileptic seizures (PNES): a South African perspective.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language that I am fluent in and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately 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 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 as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of participant**

.....  
**Signature of witness**

## Declaration by investigator

I *Gretha Cronje* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2011/12.

.....  
**Signature of investigator**

.....  
**Signature of witness**

Appendix 12: Advertisement

## Would you like to be part of a research study?

- Are you 14 years or older?
- Are you fluent in Afrikaans or English?
- Please contact Gretha Cronje at:

Tel.: 021 – 808 9019

E-mail: [gretha@sun.ac.za](mailto:gretha@sun.ac.za)

Title of study:

COPING STYLES AND QUALITY OF LIFE IN  
PATIENTS WITH PSYCHOGENIC NONEPILEPTIC  
SEIZURES (PNES): A SOUTH AFRICAN  
PERSPECTIVE

Psychogenic nonepileptic seizures (PNES) are episodes that resemble epileptic seizures (ES), but are not associated with abnormal electric discharges in the brain. These episodes are caused by an underlying psychic conflict or psychological problems and are considered to be beyond patients' voluntary control.

Ethical approval nr: N11/08/267

## Appendix 13: Health Research Ethics Committee



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19 September 2011

**MAILED**

Mrs G Cronje  
5 Carissa Street  
Somerset - West  
7130

Dear Mrs Cronje

**"Coping styles and quality of life in patients with psychogenic nonepileptic seizures (PNES): A South African perspective."**

**ETHICS REFERENCE NO: N11/08/267**

**RE : APPROVED**

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project on 14 September 2011, including the ethical aspects involved, for a period of one year from this date.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at 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. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Hélène Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). 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.

Approval Date: 14 September 2011  
19 September 2011 04:50

Expiry Date: 14 September 2012

Page 1 of 2



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health  
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support

Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa  
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jou kennisvenster • your knowledge partner

Yours faithfully

**MRS MERTRUDE DAVIDS**

**RESEARCH DEVELOPMENT AND SUPPORT**

Tel: 021 938 9207 / E-mail: [mertrude@sun.ac.za](mailto:mertrude@sun.ac.za)

Fax: 021 931 3352

19 September 2011 04:50

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Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



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## Appendix 14: Ethical approval Medi – Clinic Hospital



MEDICLINIC OFFICES  
STRAND ROAD  
STELLENBOSCH  
7600  
  
PO BOX 456  
STELLENBOSCH  
7599  
  
T +27 21 809 6500  
F +27 21 809 6756  
ETHICS LINE 0800 005 316  
  
[www.mediclinic.co.za](http://www.mediclinic.co.za)

04 October 2011

Mrs G Cronje  
5 Carissa Street  
Somerset West  
7130

E-mail: [gretha@sun.ac.za](mailto:gretha@sun.ac.za)

cc: Mr C Lake  
Mediclinic Constantiaberg  
[clive.lake@mediclinic.co.za](mailto:clive.lake@mediclinic.co.za)

Dear Gretha,

**COPING STYLES AND QUALITY OF LIFE IN PATIENTS WITH PSYCHOGENIC NONEPILEPTIC SEIZURES (PNES): A SOUTH AFRICAN PERSPECTIVE**

Please be advised that Mediclinic hereby approves the application for the above-mentioned research.

Yours sincerely,

  
MS E JORDAAN  
NURSING EXECUTIVE

MEDI-CLINIC LTD  
REG. NO. 1969/009218/06  
[www.mediclinic.co.za](http://www.mediclinic.co.za)

## Appendix 15: Ethical approval Tygerberg Hospital



Tygerberg Hospital and  
Mitchells Plain & Tygerberg Oral Health Centres  
REFERENCE: Research Projects  
ENQUIRIES: Dr M A Mukosi  
TELEPHONE: 021 938-5966

ETHICS NO: N11/08/267

*Coping styles and quality of life in patients with psychogenic non-epileptic seizures (PNES): A South African perspective.*

Dear Mrs G Cronje

### PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

A handwritten signature in black ink, appearing to read "D Erasmus", written over a horizontal line.

**DR D ERASMUS**  
**CHIEF DIRECTOR: TYGERBERG HOSPITAL**

Date: 25/04/2012

Administration Building, Francie van Zijl Avenue, Parow, 7500  
tel: +27 21 938 5966 fax: +27 21 938-6698

Private Bag X3, Tygerberg, 7505  
[www.capegateway.gov.za](http://www.capegateway.gov.za)