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Monika Urbanek BSc. (Hons)

**Regulation of emotions in individuals experiencing
psychogenic non-epileptic seizures**

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Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

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Doctorate in Clinical Psychology (D.Clin.Psychol.)

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Summary of the MRP portfolio

Section A gives an overview of psychogenic non-epileptic seizures (PNES), followed by a review of the literature on affect regulation in PNES. The empirical investigations of alexithymia, psychological defence mechanisms, coping and emotional regulation in PNES are examined. The review outlines methodological limitations of existing literature and considers clinical implications as well as directions for future research.

Section B describes an empirical study investigating emotion regulation processes in PNES. The differences between PNES patients and healthy controls were examined, using a range of self-report measures. Significant findings emerged in relation to poor understanding of emotions, negative beliefs about emotions and the use of control strategies to manage emotional experiences. Poor understanding and negative beliefs about emotions were found to be significant predictors of PNES and were associated with self-reported seizure severity

Section C provides a critical appraisal and a reflective account of the research process. It addresses specific questions regarding the development of research skills and abilities, particular learning points that occurred in the process of conducting this study, clinical practice implications and ideas for future research.

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Section A

Affect regulation in psychogenic non-epileptic seizures.

A review of the literature

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Abstract

Psychogenic non-epileptic seizures (PNES) are episodes of sudden, involuntary, time-limited changes in movement, sensation, behaviour or consciousness, which superficially resemble epileptic seizures, but are thought to be related to underlying psychological issues. Several psychological risk factors underlying the occurrence of PNES have been described in the literature. These include childhood abuse, trauma, personality profiles and family functioning. However, psychological mechanisms, which produce seizure symptoms, are still unclear. A number of theories have focused on the role of affect in the development and maintenance of PNES. Affect regulation is also an identified mechanism for a range of physical and mental health problems. This review evaluates the empirical literature on affect regulation in PNES patients. A literature search was conducted, using the following databases: PsycInfo, Medline, Cochrane and Web of Science. A total of 40 studies on alexithymia, coping, psychological defence mechanisms and emotional regulation in PNES were identified and evaluated. Whilst there is some evidence for affect regulation deficits in PNES, much remains to be learned about the nature of the processes involved. The review outlines methodological limitations of existing literature and demonstrates the need for further empirical research to inform the development of conceptual frameworks and effective psychological interventions, and to improve the quality of life of individuals with PNES.

Keywords:

Psychogenic non-epileptic seizures; Affect regulation; Coping; Dissociation; Emotions

Introduction

Psychogenic Non-epileptic Seizures

Psychogenic non-epileptic seizures (PNES) are episodes of sudden, involuntary, time-limited changes in consciousness, sensation, behaviour, and autonomic function, which superficially resemble epileptic seizures (ES) (LaFrance & Devinsky, 2004). However, PNES are not associated with abnormal cortical electrical discharges and are thought to represent an experiential or behavioural response to emotional distress (Reuber & Mayor, 2012). PNES are a significant clinical problem, with 25-30% of patients referred to epilepsy centres obtaining this diagnosis (Bodde et al., 2009). Most studies show a consistent female preponderance (Szaflarski, Ficker, Cahill & Privitera, 2000; Gates, 2002), which may be due to higher rates of sexual abuse amongst women (Bowman, 1993). Whilst historically, PNES have been considered to be a manifestation of hysteria, current classifications situate PNES as dissociative (conversion) disorders (ICD-10; World Health Organisation, 1992) or conversion ‘with seizures’, in the category of somatoform disorders (DSM-IV-TR; American Psychiatric Association, 2000).

Aetiology

Theoretical perspectives. A number of theories have been put forward to explain PNES. Psychoanalytic theories emphasise the role of trauma-related negative affect in the development of symptoms. In the 19th century, Janet (1889) proposed that hysterical symptoms arose from dissociation of traumatic memories from conscious awareness. Breuer and Freud (1893-1895/1991) suggested that ‘hysterical fits’ were a symbolic expression of a repressed sexual conflict. According to this view, one can manage the conflict between innate sexual drives and aversive feelings associated with sexual abuse, by excluding it from conscious awareness. As the neural energy of the overwhelming negative affect cannot be

discharged in the usual manner, it is converted into somatic symptoms (Roelofs & Spinhoven, 2007). Although the psychoanalytic perspective remains popular today, other ways of understanding PNES have also been suggested. These include behavioural explanations for PNES, according to which seizures are a learned pattern of behaviour (Moore & Baker, 1997) or a maladaptive coping strategy (Frances, Baker & Appleton, 1999) to deal with anxiety, maintained by positive reinforcers, such as increased attention from a family member or evasion of responsibility (Alper, 1994).

Empirical research. There is a growing recognition that individuals with PNES represent a heterogeneous group, though empirical research has lagged behind theoretical ideas (Halligan, Bass & Wade, 2000; Benbadis, 2005) and our understanding of the aetiology remains limited. A detailed description of risk factors is beyond the scope of this paper, but the main aetiological factors are outlined below (for reviews see Bodde et al., 2009; Dickinson & Looper, 2012; Reuber, Howlett, Khan & Grunewald, 2007; Reuber, 2009).

Neurological factors. A number of neurological factors have been found to contribute to the development of PNES. Structural or functional brain abnormalities are found more often in PNES patients than in the general population (Reuber, Fernandez, Helmstaedter, Qurishi & Elger, 2002). Other risk factors include history of head injuries (Westbrook, Devinsky & Geocadin, 1998), neuropsychological deficits (Cragar, Berry, Fakhoury, Cibula & Schmitt, 2002), learning disability (Silver, 1982) as well as epilepsy (Reuber et al., 2003).

Psychiatric co-morbidity. It has been estimated that more than 90% of patients with PNES have psychiatric co-morbidities (Brown, Syed, Benbadis, LaFrance and Reuber, 2011), such as anxiety and depression (Bowman, 1993; Mazza et al., 2009), post-traumatic stress disorder (Fiszman, Alves-Leon, Nunes, D'Andrea & Figueira, 2004) or personality disorders, particularly borderline personality disorder (Harden et al., 2009; Reuber, Pukrop, Bauer, Derfuss & Elger, 2004). Having a personality disorder diagnosis was found to be a more

significant predictor of PNES than a diagnosis of an axis I disorder (Direk, Kulaksizoglu, Alpay & Gurses, 2012). It is however difficult to determine causality in the relationship between PNES and co-morbid disorders, as these disorders can be a cause, an epiphenomenon, or a result of PNES (Bodde et al. 2009).

Psychosocial factors. History of childhood abuse is frequently considered integral to the development of PNES. Research has shown that rates of physical, emotional and/or sexual abuse range from 50% to 77% and are higher in PNES than in patients with epilepsy or in the general population (Fiszman, et al., 2004; Molnar, Buka & Kessler, 2001). However, studies have also shown that PNES are associated with a wide range of stressful life events, including physical abuse during adulthood, illness or death of a close friend, and high rates of bereavement (Moore & Baker, 1997; Tojek, Lumley, Barkley, Mahr & Thomas, 2000).

There is some evidence of fearful attachment and relationship problems, including higher levels of criticism and conflict in families of PNES patients, compared to families of patients diagnosed with epilepsy (Holman, Kirkby, Duncan & Brown, 2008; Moore, Baker, McDade, Chadwick & Brown, 1994; Wood, McDaniel, Burchfiel & Erba, 1998). Although PNES do not appear to be associated with a single personality profile, studies using the Minnesota Multiphasic Personality Inventory (MMPI; Butcher, 1993) have shown that PNES patients have increased scores on hysteria, hypochondriasis and schizophrenia axes (Reuber, 2008). Furthermore, the abnormality of the personality profile has been associated with the severity of PNES and the long-term outcomes (Kanner et al., 1999; Reuber, 2008).

Diagnosis and Treatment

PNES pose diagnostic and therapeutic challenges for health professionals (Francis & Baker, 1999). The diagnostic process is complex and many patients are treated for epilepsy for several years before they find out that their seizures are non-epileptic. This has numerous

implications, including potentially serious side effects of anticonvulsant medication and delays in implementation of psychological treatment (Bodde et al., 2009). Several psychological approaches, including Cognitive-Behavioural Therapy (Goldstein et al., 2010), group therapy (Barry et al., 2008), and brief psychodynamic interpersonal therapy (Mayor, Howlett, Grunewald & Reuber, 2010) have been described in the literature. Whilst the effectiveness of CBT has recently been supported by evidence from the randomized controlled trial (Goldstein et al., 2010), controlled prospective trials of psychological interventions in PNES are scarce. There is a lack of consensus regarding effective interventions and outcomes for PNES are generally considered to be poor (see reviews Gaynor, Cock & Agrawal, 2009; Martlew, Baker, Goodfellow, Bodde & Aldenkamp, 2007).

Rationale

Whilst a range of possible contributing risk factors for PNES have been identified, the psychological mechanisms that cause and maintain PNES are still unclear. According to Brown et al. (2011), treatments for PNES remain limited because a widely accepted framework for understanding this condition is lacking. It is widely assumed that PNES are closely related to emotions or even caused purely by emotions (Lesser, 2003), and stress is thought to play a major role in the onset of the PNES and the precipitation of seizures (Devinsky, Gazzola, & LaFrance, 2011), yet the role of affect regulation in PNES is unclear.

Affect regulation is a recognized psychological mechanism underlying various forms of physical and mental health problems, including anxiety, depression, substance misuse, and personality disorders as well as somatoform disorders (Berking & Wupperman, 2012; Campbell-Sills & Barlow, 2006; Linehan, 1993; Waller & Scheidt, 2006). It can be defined as a range of intrinsic and extrinsic regulatory mechanisms, used by an individual to influence their emotional experience and expression (Waller & Scheidt, 2006). According to Gross and

Thompson (2007), affect regulation is a superordinate construct, which encompasses at least four overlapping concepts: psychological defences, coping, mood regulation and emotion regulation.

Many of the psychological factors associated with PNES, such as borderline personality disorder, trauma history and insecure attachments have been associated with deficits in affect regulation (Linehan, 1993; Waller & Scheidt, 2006). Therefore, the process of regulating affective states might play a role in furthering our understanding of the psychological mechanisms underlying PNES. A review of the literature is needed to establish current understanding of how individuals with PNES regulate their affective states and to help to guide future research in the area.

Review

This review aims to examine the empirical evidence pertaining to affect regulation in PNES. Whilst affect regulation has been operationalised in many ways, for the purpose of this review, the conceptual framework developed by Gross and Thompson (2007) will be used. Details of the method, including search terms and inclusion/exclusion criteria can be found in Appendix A. Literature has been organised into four main sections: Alexithymia; Psychological Defence Mechanisms; Coping; and Emotion Regulation.

Alexithymia

Alexithymia has been defined as difficulties with the ability to identify feelings, distinguish them from somatic sensations, and describe them to others, accompanied by a concrete, externally oriented style of thinking (Nicolo et al., 2011). Research has shown alexithymia to be associated with greater levels of psychopathology (Nicolo et al., 2011), dissociation (Maaranen et al., 2005), somatic complaints (Duddu, Isaac & Chaturvedi, 2003;

Pedrosa-Gil et al., 2009) and affect dysregulation (Bagby & Taylor, 1997). There is a debate in the literature about whether alexithymia is a personality construct, which reflects a deficit in cognitive processing and emotion regulation (Bagby & Taylor, 1997; Lane, Sechrest, Riedel, Shapiro & Kaszniak, 2000), or a psychological defence mechanism, which functions to minimise emotional involvement and protect the self (McDougall, 1985; Thome, 1991; Helmes, McNeill, Holden & Jackson, 2008).

Despite the fact that alexithymia has long been thought to contribute to the development of somatoform symptoms (Berking and Wupperman, 2012), only a handful of studies have examined it in PNES. Research has focused on establishing the prevalence of alexithymia and its utility in discriminating between PNES and epilepsy, using the Toronto Alexithymia Scale-20 (Bagby, Taylor & Parker, 1994). The reported levels of alexithymia in PNES ranged between 30% (Tojek et al., 2000) and 90.5% (Bewley Murphy, Mallows & Baker, 2005). Whilst levels of alexithymia appear elevated in PNES, compared with healthy controls, alexithymia does not reliably discriminate between PNES and ES (Bewley et al., 2005; Myers, Matzner, Lancman, Perrine & Lancman, 2013; Tojek et al., 2000). This could be due to increased levels of trauma and PTSD in both groups (Rosenberg, Rosenberg, Williamson & Wolford, 2000). Alternatively, it is possible that the concept of alexithymia is too broad and therefore research should focus on specific aspects of the construct (Carson et al., 2012). Given the limitations of self-report data, future studies need to use objective measures to examine emotional awareness in PNES.

Some authors have argued that alexithymia develops in response to trauma (Taylor, 2010; Zeitlin, McNally & Cassidy, 1993); however, there is a shortage of studies examining this relationship in PNES. In a recent study alexithymia was found to be associated with trauma symptoms, such as anxious arousal, intrusive experiences, dissociation and defensive avoidance (Myers et al., 2013). The relationship between alexithymia and trauma was also

examined by Hingray et al. (2011), who compared a group of PNES patients with histories of traumatic events (n=19) to a group with no such histories (n=6) on a range of measures of psychiatric co-morbidity, dissociation and alexithymia. The findings showed that the trauma group had significantly higher scores on dissociation and ‘difficulty describing feelings’ subscale of the TAS-20. Small sample sizes and the insufficient power could explain the lack of significant findings with regards to other aspects of alexithymia. However, it is also possible that different underlying processes are responsible for the elevated alexithymia scores in each group. The use of brain imaging techniques might help to further our understanding of these processes in PNES. Overall, further research needs to examine whether alexithymia is a neurologically mediated deficit, a psychological defence mechanism or a combination of both, as this may have implications in relation to treatment (Baslet, 2011).

Psychological Defences

Psychological defences are a crucial aspect of one’s capacity to maintain emotional homeostasis (Bowins, 2004). Defences are thought to operate outside of conscious awareness and are regarded as relatively stable characteristics of an individual (Cramer, 2000; Gross & Thompson, 2007). In the psychoanalytic literature, the main function of psychological defences is regulation of aggressive and sexual impulses as well as associated anxiety (Moos & Holahan, 2003).

Dissociation. The majority of empirical investigations into psychological defences of PNES have focused on examining dissociation, an umbrella term for various processes, which change one’s level of awareness and/or the integration between memories, identity, emotions, thoughts and sensorimotor function (Carson et al., 2012). Although it is thought to protect the individual from painful emotions altering conscious experience (Bodde et al, 2009), an

extended use of dissociation might prevent acceptance and resolution of a traumatic event (Barry & Sanborn, 2001).

The literature suggests that there is a high prevalence of dissociative symptoms in PNES, with some studies reporting more than 85% of PNES patients classifying for a co-morbid dissociative disorder (Bowman, 1993; Bowman & Markand, 1996). The frequency of dissociative experiences has been found to be strongly associated with poor health-related quality of life in patients with PNES, even when the symptoms of anxiety, depression and seizure characteristics were controlled for (Mitchell, Ali, & Cavanna, 2012).

Recently, distinctions have been made between psychoform dissociation, described as an altered state of consciousness involving a sense of separation from everyday experience (e.g. depersonalisation or derealisation), and somatoform dissociation, a reversible loss of integration of somatic experiences, functions and responses (Van Der Hart, Nijenhuis, Steele & Brown, 2004; Carson et al., 2012). The majority of studies in PNES have examined the psychoform dissociation, using the Dissociative Experiences Scale (DES; Bernstein & Putnam, 1986). A number of them found that patients with PNES demonstrated a heightened tendency for dissociation, when compared with epilepsy and/or healthy controls (Ito, Adachi, Okazaki, Kato, & Onuma, 2009; Kuyk, Dyck, & Spinhoven, 1996; Mazza et al., 2009; Prueter, Schultz-Venrath & Rimpau, 2002; Van Merode et al., 2004). However, the levels of psychoform dissociation were found to be less markedly increased than expected (Goldstein, Drew, Mellers, Mitchell-O'Malley & Oakley, 2000; Goldstein & Mellers, 2006). Importantly, some studies failed to find significant results (Alper et al., 1997; Kuyk, Spinhoven, Boas & Van Dyck, 1999; Litwin and Cardena, 2001). These inconsistent findings might be explained by shared processes in both PNES and ES or very high dissociation scores of a relatively small number of PNES individuals (Reuber, House, Pukrop, Bauer & Elger, 2003). It has also been argued that DES cannot reliably discriminate between PNES and ES because PNES are

associated with somatoform, rather than psychoform dissociation (Lally, Spence, Cusker, Craig, Morrow, 2010).

Somatoform dissociation has been much less studied, but there is some evidence to suggest that measures of somatoform dissociation, such as Somatoform Dissociation Questionnaire (Nijenhuis, Spinhoven, Van Dyck, Van Der Hart, & Vanderlinden, 1996) differentiate patients with PNES from patients with epilepsy (Lally et al., 2010; Lawton, Baker & Brown, 2008; Kuyk et al., 1999). However, Lawton et al. (2008) revealed that the differences between groups were no longer significant when anxiety and depression were controlled for, suggesting a strong correlation between dissociation and psychopathology, also found in other studies (Prueter et al., 2002; Reuber et al., 2003). This also indicates that the current measures of dissociation or even the concept itself might be confounded with the general level of psychopathology (Spinhoven et al., 2004). Roelofs and Spinhoven (2007) have criticised the concept of dissociation for being over-inclusive and lacking the explanatory power.

Somatisation. A tendency to experience and communicate psychological distress in the form of somatic symptoms and to seek medical help for it is the core of somatoform disorders (Lipowski, 1988). Somatisation is characterised by the lack of integration between psychological and physical aspects of an experience (Vega, Liria, & Perez, 2005), in which affect is thought to be physiologically expressed in the body, bypassing regular automatic cognitive processing (Baslet, 2011). Overall, there appears to be strong supporting evidence for somatisation tendencies in PNES. For instance, Reuber et al. (2003) investigated somatisation, dissociation and general psychopathology in PNES (n=98) and ES patients (n=63), using self-report measures, including Screening Test for Somatoform Symptoms-2 (Rief, Hiller & Heuser, 1997), the Symptom Checklist-90-Revised (Derogatis, 1977) and the DES. Whilst all mean scores were raised in the PNES compared to the epilepsy group, only

measures of somatisation and general psychopathology discriminated between patients with PNES and epilepsy. High levels of somatisation in the PNES group were also associated with poor outcome and greater seizure severity, even after correction for dissociation and psychopathology. However, somatoform dissociation was not examined, which was a limitation of this study.

A number of empirical investigations of personality profiles demonstrated elevated somatisation scores on MMPI and MMPI-2 in PNES patients (Bodde et al., 2011; Cragar, Berry, Schmitt & Fakhoury, 2005; Owczarek, 2003). Several studies have shown that PNES patients report high incidence of somatic symptoms, which are often exacerbated by stress, e.g. hypertension and ulcers (Tojek et al., 2000), as well as chronic pain symptoms (Ettinger, Devinsky, Weisbrot, Goyal & Shashikumar, 1999). Furthermore, Tojek et al. (2000) have revealed that PNES patients have greater bodily awareness than patients with epilepsy, as measured by the Private Body Consciousness Scale (Miller, Murphy & Buss, 1981). Not only do people with PNES attend more to physical symptoms, they have been shown to be less likely to attribute their symptoms to stress or psychological factors than patients with epilepsy and to have a strong preference for medical explanation of symptoms (Stone, Binzer, Sharpe, 2004), which has also been demonstrated in relation to frequent use of health care services (Martin, Bell, Hermann, & Mennemeyer, 2003; Martin, Gilliam, Kilgore, Faught & Kuzniezky, 1998).

Dissociation, somatisation and childhood trauma. A number of empirical investigations have sought to demonstrate the relationship between dissociation, somatisation and childhood abuse. The majority of studies have reported elevated levels of childhood physical, sexual and emotional trauma and dissociation and somatisation in the PNES, compared to ES patients (Akyuz, Kugu, Akyuz & Dogan, 2004; Dikel, Fennell & Gilmore, 2003; Ozcetin et al., 2009; Proenca Castro, Jorge & Marchetti, 2011; Reilly, Baker Rhodes &

Salmon, 1999; van Merode et al., 2004). However, studies have also demonstrated that the relationship between childhood abuse and dissociation/somatisation is complex, and might be mediated by other variables, such as family functioning (Salmon, Al-Marzooqi, Baker & Reilly, 2003) or general level of psychopathology (Spinoven et al., 2004). The main limitations of the majority of research in this area include the use of cross-sectional design, which limits the conclusions regarding causality and the use of self-reported and retrospective data on trauma, which might be subject to significant bias (Dickinson & Looper, 2012).

Other psychological defences. There is a paucity of research examining other psychological defences, with only one study to date examining defence profiles in PNES. Jawad et al. (1995) compared women with PNES (n=46) and women referred to a general psychiatric outpatient clinic (n=50), using the Defence Mechanisms Inventory (Ihilevich & Gleser, 1986). The findings suggested that PNES patients achieved lower scores on projection and turning against self, and higher scores on reversal (e.g. the use of negation, denial, reaction formation and repression) and turning against others. One of the limitations of this study was that the findings were not generalisable to men. The authors hypothesised that the repressive defensive style in PNES patients was an avoidant way of dealing with negative life events, which might interfere with an individual's ability to develop intimate relationships and acquire effective coping skills. The results of this study appear consistent with some of the findings from the coping literature, discussed below.

Coping

According to the theory of stress and coping, developed by Lazarus and Folkman (1984), coping refers to the cognitive and behavioural efforts of an individual to manage external or internal challenges. In contrast to emotion regulation, coping is focused on decreasing negative affect and is thought to refer to longer periods of time, e.g. coping with

bereavement (Gross & Thompson, 2007). Lazarus and Folkman (1984) distinguished between problem-focused coping strategies (e.g. seeking social support or planful problem solving), used when an individual appraises a situation as amenable to change, and emotion focused coping strategies (e.g. escape-avoidance or positive reappraisal), employed when a situation is perceived as uncontrollable (Lazarus, 1999).

A handful of studies have sought to examine stress and coping in PNES. The findings of Tojek et al. (2000) suggest that PNES patients tend to report more stressful events over the course of their lives and rate these events as more stressful, compared with ES patients. However, differences between PNES and ES in relation to perceptions of life stress have not always been found (Frances et al., 1999). The use of different measures makes the comparisons between the studies difficult and small sample sizes limit the conclusions that can be drawn. In one of the larger studies, Testa, Krauss, Lesser and Brandt (2012) compared ES (n=20) and PNES patients (n=40) admitted to an epilepsy monitoring unit, and healthy controls (n=40), using Psychiatric Epidemiology Research Interview Life Events Scale (Dohrenwend, Askenasy, Krasnoff, & Dohrenwend, 1978). The strength of this study was that it differentiated between frequency and objective severity of life events as well as distress ratings. It also controlled for the effect of gender, education and intelligence. Whilst the groups did not differ on frequency or severity of stressful life events, PNES patients experienced significantly greater distress in relation to legal and health difficulties than healthy controls and epilepsy patients. Overall, these findings suggest that PNES patients have a tendency to appraise situations as threatening and to underestimate their ability to cope, which results in higher stress levels. This is consistent with evidence from experimental studies, which have demonstrated increased cortisol levels at rest in PNES patients (Bakvis, Spinhoven & Roelofs, 2009; Bakvis et al., 2009; Bakvis et al., 2010). Further to this, some evidence of increased vigilance to social threat has been found. In an experimental study

using an ‘emotional Stroop task’, Bakvis et al. (2009) revealed that PNES patients showed greater pre-attentive processing of negative emotional stimuli (i.e. angry faces), compared to healthy controls. This state of hypervigilance might contribute to higher levels of autonomic arousal and stress. Further research is required to determine the generalisability of these findings.

Research suggests that of all coping strategies, escape-avoidance and problem-solving seem to differentiate PNES and healthy controls, with higher scores on escape-avoidance and lower scores on planful problem solving in PNES (Frances et al., 1999; Goldstein et al., 2000; Testa et al., 2012). Furthermore, Goldstein et al. (2000) has demonstrated that dissociation, measured with the DES, was positively correlated with the escape-avoidance and negatively correlated with planful problem solving. It is however worth noting that studies have failed to find significant differences between PNES and ES in relation to coping (Frances et al., 1999; Testa et al., 2012). The lack of significant findings could be due to methodological issues, such as insufficient sample sizes, or the use of self-report measures. It is also possible that the issue of coping is more complex. It has been noted that separating problem-focused and emotion-focused strategies can be problematic, as both types of coping are interdependent and supplement each other in the coping process (Lazarus, 2000). It is also erroneous to assume that problem-solving is always a more useful strategy (Lazarus, 1999). Future research should therefore examine how the balance between the two strategies, in specific circumstances, affects the outcomes of coping (Lazarus, 2000).

Nevertheless, the findings regarding escape-avoidance coping in PNES are in line with other studies reporting tendencies for avoidance behaviours in PNES. For instance, Goldstein and Mellers (2006) found increased levels of self-reported agoraphobia in PNES patients, when compared with epilepsy controls. Further to this, Bakvis, Spinhoven, Zitman and Roelofs (2011) examined automatic threat avoidance tendencies in an experimental

study. PNES patients were slower to “approach” the negative stimuli (i.e., angry faces) than healthy controls, based on arm movements signalling approach versus avoidance. Overall, the findings regarding avoidance tendencies in PNES are relatively consistent and may to some degree account for the elevated levels of anxiety in PNES patients. Whilst avoidance may offer a short-term relief from anxiety, a consistent reliance on the use of avoidant coping is problematic, as it is likely to maintain the perceptions of situations as stressful, resulting in the long-term maintenance of anxiety (Frances et al., 1999). Furthermore, avoidance behaviours might be indicative of a particular type of emotional processing (Baslet, 2011).

Emotion Regulation

The study of emotion regulation has its roots in psychoanalytic theories of psychological defences (Breuer & Freud, 1893-1895/1991; Freud, 1946) and theories on stress and coping (Lazarus & Folkman, 1984). Gross (1998) has defined emotion regulation (ER) as processes by which individuals influence, manage, experience and express their emotions. An individual may want to reduce, intensify or maintain an affective state, depending on their goals (Gross & Thompson, 2007). These processes need to be distinguished from emotions themselves (Berking & Wupperman, 2012).

Although emotions appear integral to understanding the PNES condition, studies of emotion regulation in PNES are surprisingly scarce. Two recent studies have examined emotion regulation directly, using the Difficulties in Emotion Regulation Scale (DERS; Gratz & Roemer, 2004). Roberts et al. (2012) compared the PNES group (n=18), recruited from an epilepsy monitoring unit, with community samples of seizure-free patients with low (n=18) and high (n=18) post-traumatic stress (PTS) symptoms. The findings suggested lower baseline respiratory sinus arrhythmia, reflecting a biological vulnerability to emotion dysregulation, as well as difficulties on the DERS in the PNES group, compared with low

levels of PTS symptoms. However, there was no difference between PNES and a group with high PTS symptoms on these measures, which suggested that trauma symptoms might have accounted for some of the similarities among the groups. However, the sample sizes were small, which limited the detection of effects and reduced the generalisability of findings.

Further to this, Uliaszek, Prensky and Baslet (2012) identified two different clusters of PNES patients, recruited from academic epilepsy centres. A group of individuals in cluster 1 (n=14) had elevated scores on the DERS, showed more impairment on measures of psychological distress, had higher rates of co-morbid psychiatric diagnoses and lower quality of life. The majority of the sample (n=41) was classified as cluster 2, characterised by low scores on DERS, compared with normative data. The authors proposed that the clusters reflected two different ER styles, i.e. over-modulation and under-modulation of affect. However, these findings are preliminary. The limitations of the DERS, including the fact that the questions do not distinguish between different emotions, need to be highlighted. No power analysis was reported and the two clusters differed significantly in the number of participants, which raised concerns about the sustainability of the results in a larger sample. It is also worth noting that the PNES group responses were compared to the normative data for DERS, collected from undergraduate students, and no control group was recruited specifically for this study. There may have been demographic differences between the groups, such as educational level, that were not explored, which is a limitation of this research.

A handful of studies examined emotional expression in PNES and provided mixed findings. Prigatano and Kirlin (2009) examined affective functioning, using the Affect subtest of the Barrow Neurological Institute Screen for Higher Cerebral Functions (Prigatano, Amin, & Rosenstein, 1995), which measures affect perception and expression. PNES patients (n=23) performed worse than the ES group (n=22) on this test. One of the strengths of this study was that an objective measure of affective functioning was used. However, the authors

did not report details of performance on the affective functioning test, apart from the total score. Therefore, conclusions with regards to particular ER processes could not be drawn. Further to this, Roberts et al. (2012) demonstrated that patients with PNES showed a diminished expression of positive affect. Individuals with PNES experienced greater emotional intensity to neutral and pleasant pictures, but did not experience greater negativity than those without PNES. These findings were in contrast to the findings of Stone et al. (2004), who failed to discover differences between ES (n=20) and PNES (n=20) on difficulties expressing feelings subscale of the Illness Behaviour Questionnaire (Pilowsky & Spence, 1983). These studies have used different measures of ER, making comparisons difficult. Moreover, in the study of Stone et al., (2004) the questions about emotional expression were asked in the context of exploring illness beliefs, which might have influenced the responses. Further research, with adequate sample sizes, is required to clarify these results.

Overall, the evidence of ER difficulties in PNES is tentative, as they have not been studied in a systematic manner and many questions remained unanswered. To date, no studies have investigated particular ER strategies, such as reappraisal or suppression (Gross, 2002). Furthermore, research of individuals with mood disorders has shown that beliefs about emotions are an important aspect of emotion regulation, as they reflect ways in which emotions are experienced and can shape the type of ER strategies individuals employ (Leahy, 2002). However, studies to date have not examined these beliefs in PNES patients. This is an important area, as negative beliefs about emotions are likely to lead to experiential and situational avoidance, dissociative processes and excessive control of emotional reactions (Leahy, 2002).

Methodological Limitations

The reviewed studies need to be considered in the context of their methodological limitations. The majority of research in this area has employed an open, non-randomized, cross-sectional design, comparing patients with PNES to patients with ES. As this design limits conclusions that could be drawn with regards to causality, longitudinal studies are needed to determine whether affect regulation deficits contribute to the development and maintenance of PNES or whether these deficits develop as a result of experiencing seizures.

The lack of group differences in many studies needs to be interpreted with caution, as a large proportion of studies used small sample sizes, which limited the statistical power to detect such differences. It is hoped this preliminary evidence will encourage larger, better controlled studies to be carried out in the future. Furthermore, whilst using epilepsy patients as a control group for studies of PNES provides a useful conservative comparison group, it may be difficult to draw clear comparisons, given a different psychological profile and high prevalence of psychiatric co-morbidities, including mood (Swinkels, Kuyk, De Graaf, Van Dyck & Spinhoven, 2001) and personality disorders (Swinkels, Duijsens, & Spinhoven, 2003) in ES patients. Further to this, a significant proportion of patients have diagnosis of both ES and PNES. It would therefore be useful if studies could employ other comparison groups in the future.

Furthermore, the majority of research employed self-report measures, which whilst convenient, can be problematic, particularly given the unconscious nature of some of the concepts under review (Bargh & Williams, 2007; Mauss, Bunge & Gross, 2007). Experimental methods also have their limitations, with regards to ecological validity and conclusions that can be drawn about the long-term effects of ER strategies in certain situations (Berking & Wupperman, 2012). Future research should therefore combine the

self-report measures with experimental assessments. It is also worth noting that none of the reviewed studies employed qualitative methodology. Qualitative research focusing on experiential knowledge could enhance the relevance and quality of quantitative studies in PNES (Dickinson & Looper, 2012).

Conclusions and Future Research Directions

This review has provided an overview of the emerging research evidence for affect regulation difficulties in PNES patients. Overall, there is some supporting evidence for increased levels of alexithymia, dissociation, somatisation, avoidance coping and emotional dysregulation in PNES patients, reflecting difficulties on cognitive, somatic, emotional and behavioural levels. The need for clear definitions, indicating whether what is being measured is a state or a trait variable has emerged in relation to the affective processes (Frankel, 1994; Moos & Holahan, 2003). Psychoform dissociation received most research attention, with mixed findings reported. The evidence for other processes, particularly with regards to the specific nature of these processes in PNES, changes over time, and the relationship between different aspects of affect regulation, is limited at present.

The dearth of studies on emotional regulation in PNES is particularly puzzling, given that it is widely assumed that aetiology of PNES is closely related to emotions. Future research needs to establish how individuals with PNES process emotional stimuli, how these processes differ from other populations, what types of ER difficulties people experience and what types of emotions are involved. Gaining a comprehensive understanding of emotion regulation processes in PNES would be an important focus for future research, as it could contribute to our understanding of psychological mechanisms underlying PNES, which in turn could lead to improved treatments. As researchers still disagree on the core features of ER and it has been argued that it is an over-inclusive construct (Cole, Martin, & Dennis,

2004; Gross & Thompson, 2007), it would also be important for further research to be based on clear conceptual frameworks of ER and to clarify issues regarding definition, empirical operationalisation, development and outcomes (Cole et al., 2004).

Evidence suggests that many of the reviewed processes have been associated with trauma history. This is consistent with the view that for at least a subgroup of people with PNES, the deficits in affect regulation may develop as an expression of, or mechanism for coping with trauma-related distress (Quinn, Schofield, & Middleton, 2008). However, further research is required to explore this, taking into account the heterogeneity of the population. Future research should also identify changes in affect regulation, which are most strongly associated with the outcomes (Berking & Wupperman, 2012). It would then enable the development of implicit and explicit strategies to facilitate these changes in clinical practice.

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Section B:

Emotion regulation processes in psychogenic non-epileptic seizures

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Abstract

Objective. Despite the long history of psychogenic non-epileptic seizures (PNES), relatively little is known about the mechanisms that cause and maintain this condition. Emerging research evidence suggests that patients with PNES might have difficulties in regulating their emotions. However, much remains to be learned about the nature of these difficulties and the emotional responses of individuals with PNES. The present study aimed to gain a detailed understanding of emotion regulation processes in patients with PNES, by examining differences between PNES patients and a healthy control group with regards to intensity of emotional reactions, understanding of one's emotional experience, beliefs about emotions and control of emotional expression.

Method. A cross-sectional design was used to compare the PNES group (n=56) and the healthy control group (n=88) on a range of self-report measures.

Results. Participants with a diagnosis of PNES reported significantly poorer understanding of their emotions, more negative beliefs about emotions and more control of emotional expression than participants in the control group. Whilst intensity of emotions did not discriminate between the groups, poor understanding and negative beliefs about emotions were found to be significant predictors of PNES, even after controlling for age, education level and emotional distress. Furthermore, the presence of some emotion regulation difficulties was associated with self-reported seizure severity.

Conclusion. This study provides some evidence supporting emotion regulation difficulties in PNES population, particularly with regards to poor understanding of emotions and negative beliefs about feelings. These findings need to be replicated in future research before definite conclusions can be drawn. The need for tailored psychological therapies addressing specific emotion regulation difficulties is highlighted.

Introduction

Overview of psychogenic non-epileptic seizures

Psychogenic non-epileptic seizures (PNES) are episodes of sudden, involuntary, time-limited alteration in movement, sensation, behaviour or consciousness, which superficially resemble epileptic seizures (ES), but are not associated with abnormal electrical discharges in the brain (Hixson, Balcer, Glosser & French, 2006). PNES are classified as dissociative (conversion) disorders (ICD-10; World Health Organisation, 1992) or conversion ‘with seizures’, in the category of somatoform disorders (DSM-IV-TR; American Psychiatric Association, 2000). Most authors recognise that PNES have a psychological origin and are an unintentional manifestation of emotional distress (Reuber, 2009). A number of theories have been put forward to provide an explanation of PNES. These included a conversion of an overwhelming affect into somatic symptoms (Breuer & Freud, 1893-1895/1991), a manifestation of an intense dissociated state that functions to protect an individual from an overwhelming anxiety associated with traumatic memories (Bowman, 1993; Janet, 1889), or a learned behaviour (Moor & Baker, 1997), which can function as a maladaptive coping strategy (Frances, Baker, Appleton, 1999).

A range of psychological, psychosocial and organic risk factors for PNES have been identified in the literature and there is a growing recognition that PNES patients represent a heterogeneous group (for reviews see Bodde et al., 2009; Dickinson & Looper, 2012; Reuber, Howlett, Khan, & Grunewald, 2007; Reuber, 2009). Although the majority of patients have their first episode in early adulthood, PNES can also affect children and the elderly (Devinsky, Gazzola & LaFrance, 2011). Research has shown that psychological factors, such as dissociation, psychopathology, trauma history and attachment can predict seizure frequency in PNES and not ES patients (Lally, Spence, McCusker, Craig & Morrow, 2010). However, the aetiology of this condition and the psychological mechanisms underlying PNES

remain poorly understood (Baslet, 2012), which has negative implications for treatments and outcomes (Brown et al., 2011).

Emotion regulation is considered to be a psychological mechanism underlying various forms of mental and physical illness (Bucci 1997; Taylor, Bagby, & Parker, 1997). Importantly, somatoform disorders have been linked to particular difficulties with the ability to consciously experience and tolerate emotions, correctly identify emotions and accurately link emotions to body sensations (Berking & Wupperman, 2012; De Gucht & Heiser, 2003; Subic-Wrana, Beutel, Knebel & Lane, 2010; Waller & Scheidt, 2006). Although PNES are thought to be closely related to emotional processes and the evidence suggests a tentative link between emotion regulation difficulties and PNES, there is a paucity of research explicitly examining these difficulties in PNES. In order to provide theoretical and empirical underpinnings for the present study, the concept of emotion regulation and the existing literature on regulation of emotions in PNES will be discussed, followed by a description of an empirical investigation of emotion regulation processes in PNES patients.

Emotion regulation

Emotions are intrinsic to human nature and serve various intraorganismic and social functions (Gross, 1998). According to psychoanalytical theories of emotional development, emotions are initially experienced as solely sensorimotor phenomena, and then gradually acquire a cognitive-experiential component, which we call feelings (Krystal, 1997).

Emotional development therefore involves the integration of sensory, visceral and motoric aspects in the emotion schemas together with images and words (Taylor, 2003). This process is influenced by the caregiver's ability to be attuned to and to respond to the child's emotional states and is an important foundation for the developing capacity for emotion regulation.

Although there is no consensus with regards to the definition of emotion regulation (ER), a

number of theories have been proposed (e.g. Bucci, 1997; Gross & Thompson, 2007; Linehan, 1993; Mennin, Holaway, Fresco, Moore & Heimberg, 2007), and ER has been described as conscious and unconscious (Boden & Baumeister, 1997) processes by which individuals influence, manage, experience and express their emotions (Gross, 1998). Mennin et al. (2007), who developed an emotion dysregulation model of mood disorders, emphasised that the process of ER is dynamic and regulation occurs at different points in the process. Firstly, an important aspect of any emotional response is generation of emotion and the associated intensity of emotional experience. Heightened intensity of emotions refers to frequent experiences of strong negative affect that occur intensely, easily and quickly (Mennin et al., 2007) and might be indicative of one's difficulty in managing emotions. High sensitivity to emotional stimuli, high emotional intensity, and slow return to emotional baseline have all been associated with emotion dysregulation in patients with borderline personality disorder (Linehan, 1993). The second component of the model, necessary for effective regulation of emotions, is the capacity to understand emotional responses, i.e. the ability to recognise emotions in oneself and others, and to communicate how one feels (Goleman, 1995; Kostiuk & Fouts, 2002). Poor understanding has been found to be negatively associated with active coping (Gohm & Clore, 2002). There is a considerable overlap between the concept of poor understanding of one's emotions and alexithymia (Mennin, et al., 2007); therefore, these terms will be used interchangeably in the present paper.

The third aspect of the ER model proposed by Mennin et al. (2007) is reactivity to one's emotional states, which is related to beliefs about emotions. Negative reactivity refers to discomfort with experience of emotions, which can contribute to the development of a strong cognitive reaction that a particular emotional response is dangerous or harmful (Mennin et al., 2007). Attending to and normalising one's emotions is likely to lead to

acceptance, expression and experience of validation, whereas pathologising one's emotional experience is likely to lead to experiential and situational avoidance, dissociative processes, feelings of guilt, and excessive efforts to control (Leahy, 2002).

Finally, the process of management of emotions refers to knowing when or how to enhance or diminish one's emotional experience in a context-appropriate manner. Research has shown that strategies focused on excessive control of emotion-expressive behaviour can be problematic, as they prevent the resolution of painful experience (Rachman, 2001), fail to decrease the emotional experience and lead to ruminations about the negative events, continuous physiological arousal and physical symptoms (Stanton et al., 2000; Goldin, McRae, Ramel & Gross 2008; Gross, 2002). Inhibition of expressing emotions has been found to be a key characteristic of patients suffering from chronic pain (Pilowsky & Spence, 1976; Waller & Scheidt, 2006).

Regulation of emotions in PNES

There is some empirical evidence suggesting that the concept of ER might be relevant for the PNES population. Research has shown an increased prevalence of insecure attachment (Holman, Kirkby, Duncan & Brown, 2008), mood disorders (Bowman, 1999; Jawad et al., 1995; Krishnamoorthy, Brown & Trimble, 2001) and borderline personality disorders (Harden et al., 2009) in the PNES population. These factors have previously been linked with deficits in regulation of affect (Fonagy, Gergely, Jurist & Target, 2002; Hazan & Shaver, 1987; Mennin et al., 2007). Moreover, dissociation and somatisation tendencies are well documented in PNES (see review Baslet, 2011) and might be suggestive of potential deficit in cognitive processing of emotions as well as the lack of integration of psychological and physiological aspects of experience (Vega, Liria, & Perez, 2005). Furthermore, tendencies for avoidant behaviour, demonstrated in several studies (Bakvis, Spinhoven, Zitman & Roelofs,

2011; Frances et al., 1999; Goldstein & Mellers, 2006) could be indicative of a particular way of processing emotional information (Baslet, 2011).

Whilst it is widely assumed that PNES are closely tied to emotions and even caused purely by emotions (Lesser, 2003), there is a paucity of research investigating how PNES patients process emotional information (Uliaszek, Prensky & Baslet, 2012). A handful of studies examined alexithymia, which can be defined as poor awareness of one's emotions, difficulty with identifying and describing feelings, as well as concrete style of thinking (Nicolo et al., 2011). The prevalence of alexithymia ranged between 30% and 90.5% in PNES samples (Bewley, Murphy, Mallows & Baker, 2005; Myers, Matzner, Lancman, Perrine & Lancman, 2013; Tojek, Lumley, Barkley, Mahr & Thomas, 2000). PNES patients reported higher levels of alexithymia, when compared with healthy controls, but the differences with epilepsy samples have not always been found, particularly when anxiety and depression were controlled for (Bewley et al., 2005; Tojek et al., 2000).

Although not directly a study of ER, Prigatano and Kirlin (2009) provided some evidence of poor awareness and expression of emotional states in PNES. PNES patients (n=23) performed worse than the ES group (n=22) on the Affect subtest of the Barrow Neurological Institute Screen for Higher Cerebral Functions (Prigatano, Amin, & Rosenstein, 1995). Whilst the strength of this study was the use of an objective measure of affective functioning, the authors did not report details of test performance. Therefore, conclusions with regards to particular ER processes could not be drawn.

Emotional expression was also examined by Roberts and colleagues (2012), who investigated emotional responses to affective pictures in PNES patients. This study compared PNES patients recruited from the epilepsy monitoring unit (n=18) with seizure-free patients recruited from the community with low (n=18) and high (n=18) post-traumatic stress (PTS) symptoms. The groups did not differ in type of reported traumatic experiences. The findings

showed that PNES patients experienced greater emotional intensity when presented with neutral and pleasant pictures, but not unpleasant pictures. They did not experience greater negativity than those without PNES. Interestingly, PNES patients also demonstrated a diminished expression of positive affect (Roberts et al., 2012). These findings were in contrast to the findings of Stone, Binzer and Sharpe (2004), who failed to discover differences between ES (n=20) and PNES (n=20) on difficulties expressing feelings, as measured by an affect inhibition subscale of the Illness Behaviour Questionnaire (IBQ; Pilowsky & Spence, 1983). However, the sample sizes in this study were small and the questions about emotional expression were asked in the context of the study exploring illness beliefs, which might have influenced the responses. Overall, the findings regarding emotional expression in PNES patients are somewhat inconsistent. This could be due to methodological limitations of the studies or to the different methods used to measure emotional expression. It is also possible that the use of ER strategies varies, depending on specific emotions. However, these studies did not assess regulatory processes in relation to specific emotions, and there is generally a paucity of research in this area.

Two studies to date have used self-report measures of emotion regulation, namely the Difficulties in Emotion Regulation Scale (DERS; Gratz & Roemer, 2004). Roberts et al. (2012) demonstrated that PNES patients had more ER difficulties as measured by the DERS and lower baseline respiratory sinus arrhythmia, reflecting a biological vulnerability to emotion dysregulation, compared with individuals with low levels of PTS symptoms. No difference was found between PNES patients and a group with high PTS symptoms on these measures, perhaps suggesting that the participants in these groups shared aspects of emotional processing due to underlying trauma-related processes, shared processes not related to trauma or distinct processes. However, as mentioned above, this study had a number of limitations,

including small sample sizes, which limited the statistical power and the conclusions that could be drawn from the findings.

The DERS was also used in another recent study, conducted by Uliaszek et al. (2012). The cluster analysis showed two distinct ER profiles. One group of individuals (n=14) had elevated scores on the DERS, higher level of psychological distress, higher rates of co-morbid psychiatric diagnoses and lower quality of life. However, the majority of the sample (n=41) was characterised by low scores on DERS, compared with the normative data. The authors proposed that the clusters reflected two different ER styles, i.e. over-modulation and under-modulation of affect. However, the clusters significantly differed in size, which might have had an impact on the findings. Furthermore, the study did not use a control group, but normative data for the DERS collected from undergraduate students and the demographic differences between the groups, such as age or level of education, were not controlled for. As this study focused on identifying subgroups, it did not provide a detailed picture regarding emotion regulation processes and did not distinguish between different emotional states.

Summary and research aims

PNES is a complex disorder that remains poorly understood and managed (Dickinson & Looper, 2012). Whilst it is widely assumed that PNES are linked to deficits in ER, only a handful of studies have examined these difficulties and little is known about specific ER processes involved in PNES (Roberts et al., 2012; Uliaszek et al., 2012). Some research has shown PNES to be associated with deficits in identifying and describing feelings and a mixed picture has emerged with regards to emotional expression. Two studies to date provided some evidence of differences between groups with PNES and controls, using a self-report measure of ER. However, they used small sample sizes and did not control for variables, which may have confounded the results. Overall, PNES studies to date have not examined ER processes

in a systematic or comprehensive manner. Berking and Wupperman (2012) have highlighted that ER research needs to clarify the specific types of ER difficulties that people experience, in relation to specific emotional states. However, no studies to date have examined beliefs about emotions in the PNES population and there is a shortage of research on specific emotion regulation strategies in PNES.

Research into ER processes has important theoretical and clinical implications. Firstly, it might inform our understanding of the psychological factors and mechanisms underlying PNES and provide new theoretical insight into the role of emotions in producing seizure symptoms. It could also help to improve psychological interventions by adding an important emotional dimension (Baker, Hollaway, Thomas, Thomas & Owens, 2004), which might have a positive impact on treatment outcomes and quality of life for people with PNES.

The aim of the current research was to extend the previous findings and to provide a comprehensive understanding of ER processes in PNES, using the conceptual framework, developed by Mennin et al. (2007). The study examined four aspects of ER: intensity of emotional reactions, understanding of one's emotional states, beliefs about emotions and the extent to which individuals with PNES use emotional control strategies. Based on previous findings regarding PNES as well as other psychosomatic conditions, it was predicted that overall PNES patients would demonstrate poorer ER and report (1) heightened intensity of emotions, (2) poorer understanding of emotions, (3) more negative beliefs about emotions and (4) higher level of emotional control strategies, compared to controls. Finally, it was predicted that (5) ER difficulties would predict the presence or absence of PNES and that (6) ER difficulties would be associated with a change in seizure characteristics (frequency, severity, bothersomeness).

Method

Participants

PNES group. PNES patients were recruited from the Neuropsychiatry Services in two NHS Trusts in the South East of England. Patients were invited to participate in the study if they (1) had a diagnosis of PNES (2) were experiencing at least occasional non-epileptic seizures at the time of the study and (3) had the capacity to give informed consent.

Participants were excluded if they (1) were less than 18 years of age or (2) had a concurrent diagnosis of learning disability, autism, dementia or acquired brain injury. A total of 56 individuals with a diagnosis of PNES took part in the study, with a mean age of 39.2 years ($SD=13.60$, range 18 to 71). Table 1 displays demographic characteristics of both groups of participants. There was a significant variability in the frequency and severity of seizures experienced by participants in the PNES group. Seizure characteristics are presented in Table 2.

Healthy control group. The healthy control (HC) group was recruited through a university and a social networking site. Participants were included if they: (1) had no history or evidence of seizure activity. They were excluded if they (1) were less than 18 years of age; (2) had a long-term neurological or health condition (e.g. fibromyalgia, chronic fatigue syndrome, brain tumour, head injury or stroke) or (3) had a severe psychiatric disorder (e.g. schizophrenia, bipolar disorder or personality disorder) or a history of self-harm. A total of 88 participants comprised the final sample, with a mean age of 27.2 years ($SD=9.32$, range 18 to 56).

Table 1. Demographic characteristics of the two groups

	PNES group (n=56)	Control group (n=88)
Gender		
Male	20 (36%)	26 (30%)
Female	36 (64%)	62 (70%)
Age	M=39.2 (13.6)	M=27.2 (9.3)
18-30	19 (34%)	66 (75%)
31-40	7 (13%)	12 (14%)
41-50	17 (30%)	7 (8%)
51-60	12 (21%)	3 (3%)
61 or more	1 (2%)	-
Ethnicity		
White British	50 (89%)	69 (78%)
White Irish	1 (2%)	3 (3%)
Any other White background	2 (4%)	13 (15%)
Asian or Asian British Indian	-	1 (1%)
Asian or Asian British Pakistani	2 (4%)	-
Black or Black British Caribbean	1 (2%)	-
Any other Mixed background	-	1 (1%)
Prefer not to state	-	1 (1%)
Education		
Primary, Secondary School, O levels	23 (42%)	-
A levels, Diploma, Trade Certificate	22 (40%)	37 (42%)
University degree	10 (18%)	51 (58%)

Table 2. Seizure characteristics of PNES patients

Seizure variable	
Age at onset	M=32.0 (15.2)
Age of diagnosis	M=35.9 (14.6)
Average time till diagnosis (years)	M=4.6 (7.8)
Seizure free in the last 12 months	Range from 9hrs to 9 months
Seizure frequency in the last month	M=11.6 (16.0) Mdn=5.0 (0-84)
5 or less	26 (51%)
6-10	6 (12%)
11-15	5 (10%)
16-20	3 (6%)
21-25	2 (4%)
26-30	-
30 or more	9 (18%)
Seizure severity in the last month:	
1 (very mild) – 7 (very severe)	M=4.2 (1.9) Mdn=4 (1-7)
Seizure bothersomeness in the last month:	
1 (no bother at all) – 7 (very bothersome)	M=5.0 (1.7) Mdn=5 (1-7)

Measures

Affect Intensity Measure (AIM; Larsen & Diener, 1987; Appendix S) was used to examine the intensity of emotional reactions. The AIM is a widely used 40-item self-report questionnaire, which assesses the intensity of emotional responses to both negative and positive emotionally salient life events. The items are rated on a 6-point scale, ranging from “never” to “always”. Adequate internal consistency, convergent and discriminate validity have been established for this measure (Larsen & Diener, 1987). Test-retest reliability of 0.81 after three months has also been demonstrated (Larsen & Diener, 1987). The AIM had a good internal consistency in the present study, as the Cronbach’s alpha reliability was .852.

The Toronto Alexithymia Scale-20 (TAS-20; Bagby, Parker & Taylor, 1994; Appendix T) was used as a measure of understanding one’s own emotions. It is a well-established and widely used self-report scale, consisting of 20 items, rated on a 5-point scale, ranging from “strongly agree” to “strongly disagree”. A total score greater than 60 represents alexithymia (Bagby, Taylor & Parker, 1994). The TAS-20 has shown good internal consistency (Cronbach’s $\alpha=.81$; Bagby, et al. 1994; and .85: Mennin et al. 2007). Furthermore, the TAS-20 demonstrated adequate test-retest reliability ($r=.77$, $p<.01$), and adequate levels of convergent validity and concurrent validity (Bagby et al., 1994). In the present study, internal consistency of the TAS-20 was very good (Cronbach’s $\alpha=.906$).

The Beliefs about Emotions Questionnaire (Manser, Cooper & Trefusis, 2012; Appendix U) was used, as it measures a range of specific beliefs about feelings. The subscales examine beliefs about emotions as overwhelming and uncontrollable; shameful and irrational; invalid and meaningless; useless; damaging; and contagious. The scale is composed of 43 items that are rated on a 5-point scale, ranging from “strongly disagree” to “strongly agree”. The BAEQ demonstrated good internal consistency (0.69-0.88) and adequate test-retest reliability. Adequate convergent and divergent validity were also reported

(Manser, et al., 2012). In the present sample, the Cronbach's alpha reliability was good ($\alpha=.898$).

The Courtauld Emotional Control Scale (CECS; Watson & Greer, 1983; Appendix V) was used to measure a tendency to control emotional reactions. The CECS consists of 21 items, scored on a 4-point scale, ranging from "almost never" to "almost always". An important aspect of this scale is that it has three subscales, indicating control of different affective states, namely anger, anxiety and depressed mood. The CECS demonstrated good internal consistency of 0.86 for the (anger subscale) to 0.88 (anxiety and depressed mood) and good test-retest reliability (0.84-0.95) (Watson & Greer, 1983). The CECS showed very good internal consistency in the present study ($\alpha=.928$).

The Hospital Anxiety & Depression Scale (HADS; Zigmond & Snaith, 1983; Appendix W) is a 14-item screening tool for anxiety and depression. Items are scored on a 4-point scale and assess feelings and behaviours during the previous week. Total scores can fall into four categories: normal (0-7), mild (8-10), moderate (11-15) and severe (16-21). The scale has been widely used in research and has demonstrated good validity and reliability. Cronbach's alpha of 0.80 for the anxiety scale and 0.76 for the depression scale were reported (Bjelland, Dahl, Haug, & Neckelmann, 2002; Mykletun, Stordal, & Dahl, 2001). The sensitivity and specificity for both anxiety and depression scales were reported to be sufficient to detect caseness and symptom severity within a wide range of psychosomatic, psychiatric and healthy populations (Bjelland et al., 2002). In this study, HADS had a good internal consistency, as Cronbach's alpha of .882 was found.

Procedure and ethical considerations

Ethical approval was obtained from the NHS Ethics Committee (Appendix B). Further Approval was granted by the Research and Development Departments (R&D) within

the participating trusts (Appendices C and D). Potential participants with a diagnosis of PNES were identified by clinicians, who reviewed the case notes to ensure mental capacity. Typically, the information sheet (Appendix G), describing the purpose and the research procedure, was sent out by post. The right to withdraw was clearly stated and participants were informed that their health care was not contingent on their participation in this project. If no contact was made by a participant within 2-3 weeks of receiving the letter, the researcher made a follow-up phone call in order to give participants an opportunity to ask questions or discuss any issues regarding the study.

Participants were given a choice of whether they wished to come to the clinic or complete the questionnaires at home and return them in an envelope provided. Five participants chose to meet the researcher and complete the questionnaires in the clinic. During the meeting, the study was discussed in detail and participants were given an opportunity to ask questions. Following this, written informed consent was obtained (Appendix F). Participants were asked if they wished to take part in a prize draw and if they wished to receive a summary of the findings. The demographic questionnaire (Appendices Q and R) as well as the measures described above were then administered.

With regards to the control group, an online survey containing the measures was set up, in order to approach a wide range of participants. Once permission was gained (Appendix E), an email inviting students to complete the questionnaires online (Appendix J) was circulated to three different university departments. Further participants for the control group were recruited through a social networking site.

Confidentiality was discussed either verbally or in writing, and all participants were given contact details for the researcher. Contact numbers and websites of organisations that offer emotional support were provided, if participants wished to further discuss the issues resulting from participation in this study. Anonymised data were kept electronically on a password-protected spreadsheet. Following data analysis, a report with research findings was

sent to participants (Appendix P). In addition, a summary was sent to the R&D departments and the ethics committee (Appendix O), together with the end of study declaration (Appendix L).

Power calculation

There are no studies in the literature that report the effect sizes required for the power calculation. A priori power calculations, using the Gpower software (Erdfelder, Faul & Buchner, 1996), based on medium effect size (Cohen, 1969), a significance level of 0.05, and a power of 0.80 suggested that t-test sample size required for each group was 64, whilst total sample size for logistic regression was 88, with 0.05 level of significance, odds ratio of 2.0 and a power of 0.80. According to Field (2009) a minimum of 15 participants per predictor variable is required to achieve sufficient power for regression analysis.

Results

Inspection of data

Data were analysed using the SPSS software (Version 18.0). A small amount of missing values was present in data from the clinical sample. Analysis using the Little's Missing Completely at Random Test (MCAR) resulted in Chi-Square=1640.470 (df=1622, $p=.37$). These results indicated that data were missing in a random, rather than systematic way. Subsequently, the expectation-maximization technique was used to deal with the missing data. Exploratory analyses revealed a small number of outliers. The Outlier Labelling Rule ($g=2.2$) (Hoaglin & Iglewicz, 1987), was then used and subsequently, one outlier was removed.

Exploratory analyses were conducted to establish whether the assumptions for parametric statistics were met. The Levene's test was used to explore the homogeneity of

variance. The examination of the Kolmogorov-Smirnov test, histograms and q-q plots for each group of participants revealed that a number of variables did not meet the assumption of normal distribution (Appendix X). Therefore, transformations, including log transformation and square root transformation (Field, 2009) were performed to determine whether the normality of the distributions could be improved. However, the transformations were only effective for some variables, and therefore they were not used in the analysis. Consequently, the non-parametric statistics, such as Mann-Whitney U test, were used for variables which were not found to be normally distributed.

The assumptions for the logistic regression analysis were then explored. The examination of the collinearity between variables indicated that the Variance Inflation Factor values were all considerably below 10, and the tolerance values were all above 0.1, indicating no multi-collinearity issues between the potential predictor variables (Pallant, 2010). Additionally, the linearity of the logit was assessed (Field, 2009). The interaction between each of the predictor variables and its log transformation were not found to be significant, indicating that the predictors were linearly related to the log of the outcome variable.

Demographic and clinical characteristics

Both groups were predominantly female (PNES: 64% female; control group: 70% female). The chi-square tests for independence indicated that gender ($\chi^2(1)=0.599$, $p=0.439$) and ethnicity ($\chi^2(1)=2.822$, $p=0.093$) were not significantly associated with group membership. However, there was a significant association between group membership and education level ($\chi^2(1)=31.022$, $p<.001$). Data showed that 5% of PNES patients and 50% of participants in the control sample completed a university degree. In addition, the PNES patients ($Mdn=41.5$) were found to be older than the control participants ($Mdn=25$). This difference was significant ($U=1225$, $z=-5.084$, $p<.001$, $r=-.42$).

The Mann-Whitney U test was used to determine if there were differences between groups on anxiety and depression symptoms. The results indicated that PNES patients scored higher than HC participants on both anxiety and depression subscales. These differences were statistically significant (Table 3). The proportion of participants, who were within the ‘clinical’ range (>10) (Snaith, 2003) for anxiety in the PNES group (54%) was higher compared to the control group (28%). This difference was statistically significant ($\chi^2(1)=9.179$, $p=.002$). Similar results were found in relation to the depression subscale, as 23% of PNES and 6% of the control group classified as depressed. This difference was statistically significant ($\chi^2(1)=9.618$, $p=.002$).

The relationship between emotional distress and ER difficulties was examined across both groups, using Spearman’s correlation coefficient. Symptoms of anxiety and depression were positively correlated with total scores on the AIM, TAS-20, BAEQ and CECS. These associations were statistically significant (Table 4).

Table 3. Group differences on the HADS

	PNES (n=56) Median (Range)	Control group (n=88) Median (Range)	U statistic	Effect size
Total	17.5 (3-34)	11 (1-32)	$U=1220^{***}$, $z=-5.103$	$r=-.43$
Anxiety	11 (2-20)	8 (1-20)	$U=1187^{***}$, $z=-3.676$	$r=-.31$
Depression	7 (0-19)	3 (0-12)	$U=1569^{***}$, $z=-5.252$	$r=-.44$

*** $p<.001$; (two-tailed)

Table 4. Correlations between emotional distress and emotion regulation difficulties

	Affect intensity	Understanding of emotions	Beliefs about emotions	Control of emotions
Emotional distress	.185*	.601***	.635***	.414***

*** $p<.001$; ** $p<.01$; * $p<.05$ (two-tailed)

Hypotheses 1-4

A series of independent samples t-test and Mann-Whitney U tests were conducted to determine whether PNES patients showed difficulties in ER. On average, PNES patients obtained higher scores on the AIM ($M=146.42$, $SD=23.45$) than HC participants ($M=141.03$, $SD=16.60$). This difference was not significant ($t(90)=1.50$, $p=.069$). As hypothesised, the PNES group reported significantly higher scores on all subscales of the TAS-20 than the control group. Effect sizes for these comparisons ranged from moderate to large (Table 5). The prevalence of alexithymia (TAS-20 total score >60) in the PNES group (63%) was considerably higher compared to the control group (14%). This difference was found to be statistically significant ($\chi^2(1)=37.165$, $p<.001$).

On average, PNES patients ($M=135.2354$ $SD=20.60$) scored higher on the BAEQ questionnaire than the control group ($M=110.86$, $SD=15.42$). This difference represented a large effect size and was significant ($t(94)=7.6$, $p<0.001$). The examination of subscales showed that PNES patients had significantly higher scores on the subscales measuring beliefs about emotions as overwhelming and uncontrollable, shameful and irrational, contagious, useless and damaging, compared to the controls. Effect sizes ranged from medium ($r=-.25$) to large ($r=.51$). Although PNES patients scored higher on the ‘beliefs about emotions as invalid and meaningless’ subscale than HC participants, this difference was not statistically significant ($U=2300.00$, $z=.675$, $p=.250$). Finally, the scores on the CECS were significantly higher for patients with PNES than HC ($U=1867.50$, $z=-2.446$, $p=.007$). Significant differences were found for the anxiety and sadness subscales, but not the anger subscale.

Table 5. Group differences on measures of emotion regulation

	PNES (n=56): Mean (SD), Median (Range)	Control group (n=88): Mean (SD), Median (Range)	Comparison statistic T-test/ Mann-Whitney U	Effect size
Affect intensity	M=146.42 (23.45)	M=141.03 (16.60),	t (90)=1.50, p=.069	r=.15
Understanding of emotions (alexithymia)	Mdn=64.94 (30-91)	Mdn=41.50 (22-76)	U=594.50, z=-7.664, p<0.001***	r =-.64
Difficulty identifying feelings	Mdn=25 (11-35)	Mdn=13.00 (7-32)	U=478.50 z=-8.145, p<0.001***	r =-.68
Difficulty describing feelings	Mdn=18 (7-25)	Mdn=11.00 (5-25)	U=840.50 z=-6.664, p<0.001***	r =-.56
Externally oriented thinking	Mdn=22 (9-34)	Mdn=17.00 (9-28)	U=1473.50 z=-4.068, p<0.001***	r =-.34
Beliefs about emotions	M=135.2354 (20.60)	M=110.86 (15.42)	t (94)=7.6, p<0.001***	r =.62
Overwhelming	M=32.20 (7.58)	M=24.44 (6.55)	t (142)=6.51, p<0.001***	r =.48
Shameful	Mdn=26.00 (12-41)	Mdn=17.50 (10-38)	U=1143.00 z=-5.420 p<0.001***	r =-.45
Invalid	Mdn=23.00 (15-30)	Mdn=22.00 (13-27)	U=2300.00 z=-.675 p=.250	r =-.06
Useless	Mdn=27.50 (13-37)	Mdn=24.50 (12-35)	U=1724.00 z=-3.041 p=.001**	r =-.25
Damaging	M=14.18 (4.43)	M=10.36 (3.07)	t (89)= 5.65, p<0.001***	r =.51
Contagious	Mdn=14.00 (8-20)	Mdn=12.00 (4-19)	U=1277.00 z =-4.898 p<0.001***	r =-.41
Control of emotions	Mdn=56.00 (31-84)	Mdn=49.00 (27-82)	U=1867.50 z=-2.446 p=.007**	r =-.20
Angry	Mdn=18.00 (7-28)	Mdn=16.00 (8-28)	U=2144.50 z=-1.313 p=.095	r =-.11
Anxious	Mdn=20.00 (10-28)	Mdn=17.00 (7-28)	U=1929.00 z=-2.200 p=.014*	r =-.18
Unhappy	Mdn=18.50 (12-28)	Mdn=16.00 (9-28)	U=1862.50 z=-2.471 p= .007**	r =-.21

*** p<.001; ** p< .01; *p <.05 (one-tailed)

Hypothesis 5.

Firstly, as a preliminary step, correlations between predictor variables and the outcome were explored. Point-biserial correlations between group membership (absence or presence of PNES) and the predictor variables, totals on AIM, TAS-20, BAEQ and CECS were carried out (Table 6). The TAS-20 was positively associated with group membership ($r_{pb}=.64$, $p<.01$), suggesting that the higher the score on the TAS-20, the more likely the participant was to belong to the PNES group. Significant positive correlations were also found between BAEQ score, CECS score and age, and the presence of PNES. Furthermore, correlation coefficient can be used to indicate effect size (Field, 2009). The results showed small effect sizes for the AIM and CECS as well as large effect sizes for the TAS-20 and BAEQ. The AIM was positively correlated with the group membership. This correlation was not statistically significant ($r_{pb}=.134$, $p=.109$).

Table 6. Point-biserial correlations between predictor variables and group membership

	Affect intensity	Understanding of emotions	Beliefs about emotions	Control of emotions	Anxiety and depression	Age
Group	.134	.640***	.562***	.192*	.421***	.465***

*** $p<.001$; ** $p<.01$; * $p<.05$ (two-tailed)

In order to find the set of predictors which best distinguished between the PNES and the control group, hierarchical binary logistic regression was carried out, using the forced entry method. In order to control for the effect of age and education, these variables were added as covariates in step one, whilst the predictor variables were added at step two. These included the TAS-20, BAEQ, CECS and HADS, as they were found to be significantly correlated with group membership.

The results showed that the addition of the predictor variables statistically added to the model, which was found to be statistically significant, omnibus $\chi^2(8)=120.877$, $p<.001$. This model had a pseudo R-square of .573 using the Cox and Snell statistics and pseudo r-square of .780, using the Nagelkerke statistics, indicating that the predictor variables explained approximately 78% (Nagelkerke, R square) of the variance in group membership. The results of the Hosmer and Lemeshow test indicated support for the model, as the value was larger than .05 ($\chi^2(8)=6.510$, $p=.590$). The predictive capacity of the model was good, as it correctly classified 90.8% of cases. In addition, the Wald statistic indicated that of the predictors included alexithymia and beliefs about emotions were significant (Table 7). Anxiety and depression score and the control of emotions score were not found to be significant predictors of group membership. The strongest predictor was poor understanding of emotions, with an odds ratio of 1.11 suggesting that as the score on the TAS-20 increases, the likelihood of having PNES increases by 1.11 times. The odds of having PNES are 1.11 greater with one-unit increase in the TAS-20. In other words, the odds are increased by 11%. It is also worth noting that when HADS was entered at step one, the TAS-20 ($p=.005$) and BAEQ ($p=.047$) remained significant predictors.

Following the regression analysis, diagnostic statistics, such as Cook's distance, DFBeta and standardized residuals were examined. These analyses suggested that Cook's distance values were all below 1, but a couple of cases in the clinical sample demonstrated high values of DFBeta and standardized residuals. They had low scores on some of the emotion regulation variables, potentially having some effect on the model. These data points were not entered incorrectly and diagnostics should not be used as a way of justifying the removal of data points to effect some desirable change in the regression parameters (Field, 2009). Therefore, it was considered appropriate for them to remain in the model. The implications are considered in the discussion section.

Table 7. Logistic regression analysis results, adjusting for age and education level.

Predictor	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Understanding of emotions	.105	.037	7.956	1	.005**	1.111	1.033	1.195
Beliefs about emotions	.046	.023	3.948	1	.047*	1.047	1.001	1.096
Control of emotions	-.022	.033	.431	1	.512	.979	.917	1.044
Anxiety and depression	-.091	.064	2.036	1	.154	.913	.806	1.035
Constant	-13.890	3.267	18.077	1	.000***	.000		

*** p<.001; ** p< .01; *p <.05

Hypothesis 6.

The relationships between ER processes and seizure characteristics were then explored in the PNES group, using Spearman's correlations. There was a medium positive correlation between seizure severity and BAEQ total ($r=.309$, $p=.027$). Similarly, medium positive correlations were found between seizure bothersomeness and BAEQ score. The analysis also indicated that small positive correlations were found between seizure severity and TAS-20 ($r=0.290$, $p=.039$). No significant correlations were found between ER processes and seizure frequency. The results of the correlation analysis are presented in Table 8.

Table 8. Correlations between seizure characteristics and emotion regulation

	Affect intensity	Understanding of emotions	Beliefs about emotions	Control of emotions
Seizure Severity	.111	.290*	.309*	.107
Seizure Bothersomeness	.091	.234	.372**	-.009
Seizure Frequency	.017	.200	.187	-.142

*** p<.001; ** p< .01; *p <.05 (two-tailed)

Discussion

The aim of this study was to investigate ER processes in a group of patients diagnosed with PNES, compared to healthy controls. This research expanded on the previous literature and provided some evidence for ER difficulties in the PNES population. On average, PNES patients had higher scores on affect intensity than the participants in the control group. However, contrary to the hypothesis, this difference was not statistically significant. Previous research demonstrated that PNES patients showed greater emotional intensity when presented with neutral or pleasant pictures, but not when presented with negative stimuli (Roberts et al., 2012). This is the first time that the AIM has been used with the PNES population, limiting the comparisons between studies. The AIM does not clearly distinguish between positive and negative emotions, as typically one total score is calculated. This might account for the discrepancy in findings. Future research should aim to measure the intensity of positive and negative emotions independently.

Although methodological issues need to be considered, it is also possible that PNES patients do not perceive their emotional experiences as more intense than other people. This is consistent with somatisation theories, according to which affect is converted into somatic symptoms, bypassing cognitive processing (Baslet, 2011). Previous research has shown that PNES patients tend to report physical symptoms and are less likely to attribute their symptoms to stress or psychological factors (Stone et al., 2004). In addition, difficulties with identifying and describing feelings, identified in the sample, suggest a possible disconnection between the physical and cognitive aspects of emotional experience, and might go some way to explain the findings regarding affect intensity. Further evidence is needed to clarify this aspect of emotional functioning in PNES.

The findings of this study also demonstrated that PNES patients had more difficulties with identifying and describing feelings, as well as higher levels of externally orientated

thinking than controls. Furthermore, the clinical levels of alexithymia in the PNES group were significantly higher compared to the control group. This is in line with previous research in PNES (Bewley et al., 2005) and other somatoform disorders (Subic-Wrana et al., 2010; Waller & Scheidt, 2006), suggesting deficits in emotional awareness and understanding of one's own feelings. The levels of reported alexithymia in this study were relatively high, as 63% of PNES participants were within the clinical range, compared with 14% of healthy controls. A large effect size was found when comparing the two groups and poor understanding of emotions was shown to be a significant predictor of PNES, even when age, education and emotional distress were controlled for. As far as it is known, this is the first study to suggest that levels of alexithymia in PNES population are positively associated with self-reported seizure severity. This finding has important treatment implications, as patients with difficulties understanding their emotions might be more likely to perceive their seizures as severe and experience high levels of emotional distress. Given the early stage of research in this area, these results would need to be replicated before definite conclusions can be drawn.

As hypothesised, PNES patients reported more negative beliefs about emotions. This difference was significant in relation to 'beliefs about emotions as overwhelming and uncontrollable', 'beliefs about emotions as shameful and irrational', 'beliefs about emotions as damaging', 'beliefs about emotions as contagious' and 'beliefs about emotions as useless'. Overall, beliefs about emotions were also found to be a significant predictor of PNES, even when age, education and emotional distress were controlled for. This is an important finding, as it is the first time beliefs about emotions have been associated with an increased likelihood of experiencing PNES. Interestingly, beliefs about emotions were also significantly associated with perceived seizure severity and the degree to which participants were bothered by their seizures. These findings are in line with the literature on mood disorders, indicating a

relationship between positive beliefs about emotion and emotional well-being (Leahy, 2002; Mennin et al., 2007). They also have potentially useful implications in relation to treatment. However, these results need to be replicated in future research before definite conclusions can be drawn.

As hypothesised, the extent to which people controlled their emotions was significantly higher in the PNES group when compared with controls, providing some support to previous findings (Prigatano & Kirlin, 2009; Roberts et al., 2012). It is also worth noting that there was a significant correlation of medium strength between the use of control strategies to deal with emotions and emotional distress. However, whilst the emotional control of anxious and depressed states was elevated, the control of anger was not significantly higher in the PNES group. This is an interesting finding, given the elevated levels of anxiety and depression in the PNES sample. It is consistent with the theory and research on emotional inhibition, indicating that controlling an emotional response often fails to decrease emotional experience (Stanton et al., 2000; Goldin, McRae, Ramel & Gross 2008; Gross, 2002; Waller & Scheidt, 2006). As no measure of anger symptoms was included in this study, future research needs to examine the frequency and severity of anger symptoms and how they relate to the strategies of managing this emotion in PNES.

It is also worth noting that the results of regression analysis showed that the use of control strategies for ER was not found to be a significant predictor of PNES, when age and education were controlled for. These inconsistencies might be due to the fact that other predictors in the regression analysis were more significant than the control of emotions. Furthermore, methodological issues, including sample size and the limitations of the use of self-report measures of affect expression might have influenced the results. Whilst this study focused entirely on negative emotions, it would be helpful for future research to distinguish between positive and negative emotions, as it is possible that PNES patients control the

expression of positive emotions more than the expression of negative emotions, as shown by Roberts et al. (2013). Furthermore, whilst this study focused on a particular strategy, future research should examine a range of ER strategies and the flexibility with which patients with PNES apply specific ER strategies, depending on the situational demands (Hofmann, Sawyer, Fang & Asnaani, 2012).

Methodological considerations

The results of this research need to be considered in the context of the methodological limitations. This study employed a cross-sectional design, which limited the conclusions that could be drawn from the findings with regards to causality. However, given the exploratory nature of this research, as well as the timescale of the project, a cross-sectional design seemed appropriate. Studies, using longitudinal design, need to determine whether emotion regulation difficulties are the causal or maintaining factor in PNES, or the result of having seizures. Similarly, there is a degree of circularity between the concepts of emotion regulation and symptoms of anxiety and depression. Present findings showed associations between emotional distress and emotion regulation processes. However, the two predictors of PNES remained significant even when emotional distress was controlled for. It could therefore be argued that the emotion regulation processes are shaped by early experiences and influenced by subsequent life events, impacting on the way an individual processes emotional stimuli. It is possible that the ineffective processing of emotions may put an individual at risk of developing emotional distress, particularly when faced with traumatic life events, and perceiving their seizures as more severe. Nonetheless, the relationship between emotion regulation and psychopathology requires further investigation.

Furthermore, it could be argued that the use of a comparison group, predominantly consisting of university students, was a limitation of the study, as the two groups were shown

to differ on a number of demographic variables. In order to account for this, some of the variables were controlled for in the analysis. It needs to be noted that whilst the majority of research investigating PNES have used epilepsy control groups, the validity of such comparisons has been questioned, given different underlying psychological factors (Mercer, Martin & Reuber, 2010). In addition, given the exploratory nature of this study, it was important to establish the differences between PNES and healthy controls before making comparisons with other clinical populations. It would be an important focus for future research to replicate the current findings with other comparison groups.

It is unclear if prescribed medication or psychological treatment had an impact on participants' experience of emotion and therefore influenced the findings. Whilst the aim was to recruit individuals newly referred to the service, this was not formally monitored and it therefore needs to be explored in future research. Furthermore, because most participants in the sample were White British, the generalisability of findings to other ethnic groups is limited and future research needs to explore the cultural differences associated with ER.

It is also worth noting that the current findings might have been influenced by the heterogeneity in the sample. The diagnostics following regression analysis indicated a handful of PNES cases with low scores on ER variables, which could have had an impact on the model. However, it was unclear whether these data points were unusual results or whether they were representative of a subgroup within the sample. It could be hypothesised that the small number of cases with low scores on ER variables were part of a subgroup, characterised by Uliaszek et al. (2012) as over-modulating emotions. The issue of heterogeneity was not a focus of this study, but is an important one and needs to be examined in further research.

Finally, the use of self-report measures to examine ER in PNES patients needs to be considered. Whilst self-report measures are easy and quick to administer, and measure dispositional tendencies toward certain ER strategies by assessing what participants do across

different contexts, they may be influenced by negative moods or self-presentation biases (Aldao, Nolen-Hoeksema, & Schweizer, 2010). In addition, it has been questioned whether individuals can accurately self-report on their ER processes and patients with PNES may have particular difficulties with self-reflection, which might potentially influence the validity and reliability of self-report data (Bewley et al., 2005). Whilst seizure frequency was not found to be associated with ER, this might have been due to the subjective nature of the measure. Future research should therefore combine the self-report measures of ER and seizure characteristics with observational, physiological or neuroimaging data.

Clinical implications

The findings of this study have a number of clinical implications. Firstly, the results indicated that a significant proportion of PNES patients scored in the clinical range for anxiety and depression. This demonstrates that PNES patients have significant psychological needs that should be addressed by services. Although tentative, the findings of this study also contribute to the literature suggesting a possible role of ER processes in PNES. Deficits in ability to identify and describe feelings, as well as negative beliefs about emotions appear to be of particular significance. These processes are important as they appear to be associated with personal experiences of seizure severity, and have been found to lead to experiential and situational avoidance and dissociative processes (Leahy, 2002). Interventions designed to help the person normalise their emotional states and develop more positive beliefs about emotions, whilst increasing adaptive emotional expression, may therefore be beneficial. In addition, therapy could help the patient develop an understanding of their emotional responses by connecting the cognitive and somatic aspects of their emotional experience. As PNES patients represent a heterogeneous population, it is crucial that the interventions are

tailored to an individual emotional style, taking into account deficits in emotional development, traumatic life events as well as specific ER difficulties.

Studies examining the effectiveness of psychological treatments for PNES are currently scarce. Some evidence has been found for Cognitive-Behavioural Therapy (Goldstein et al., 2010); however further research is required to establish effective interventions. The present findings suggest that therapies which specifically focus on emotion regulation difficulties, e.g. Acceptance and Commitment Therapy (Hayes, Luoma, Bond, Masuda & Lillis, 2006) and Dialectical Behaviour Therapy (Linehan, 1993) could be effective for patients with PNES, as they help people to develop skills in tolerating distressing emotions and regulating emotions effectively. Research needs to examine whether different subgroups of PNES patients respond better to different psychological approaches.

Conclusion

In conclusion, the results of the present study suggest that PNES are associated with higher levels of alexithymia, more negative beliefs about emotions and higher use of emotional control strategies. In addition, poor understanding of emotions and negative beliefs about emotions were found to be significant predictors of PNES, even when age, education and emotional distress were controlled for. These results are largely consistent with previous literature, but this study goes further in bringing together different aspects of ER, including beliefs about emotions, which have not been examined before. The findings highlight the importance of considering ER difficulties in psychological formulation and treatment of PNES. Further research is required to replicate current findings and further examine the complex ER processes in the PNES population.

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Section C:
Critical Appraisal

Word Count: 1970

This section provides a critical appraisal of the study and a reflective account of the research process. It is structured to address four specific questions designed by the clinical programme.

Question 1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

The present study, which is the largest research project I have conducted thus far, provided me with various opportunities for learning and skill development. Areas of most significant development for me included literature review, data collection, statistical analysis, and dissemination of results.

The process of reviewing the existing theoretical and empirical literature on PNES was one of the most intellectually challenging tasks I have undertaken during the clinical training. Due to the breadth and complexity of the literature on the aetiology of PNES, it was difficult to find an appropriate focus for the review. This task has helped me to considerably develop my skills in critically reviewing, analysing and synthesising a large amount of theoretical and empirical literature, and communicating the results concisely, within a limited word count.

As the design of my study involved comparing groups, I developed skills in relation to recruitment of both non-clinical and clinical samples. Firstly, I have learnt how to set-up online questionnaires and use the internet to recruit healthy control participants. This is an increasingly popular way of carrying out research, as it enables access to a wide range of populations across the world. It is also convenient for researchers as well as participants. In the future, I would like to learn about more sophisticated programs that allow researchers to set up online experiments.

Furthermore, I acquired skills in relation to conducting research in the NHS. The process of obtaining ethical approval in the NHS was a valuable experience. Whilst filling out the application form was laborious and time-consuming, the questions enabled me to think through the details of my project and develop a clear research proposal. In addition, I have also become aware of the process of data collection for research at this level. I had not anticipated the amount of work and time involved in recruiting participants for this project. Co-ordinating data collection in two NHS trusts, recruiting a control sample, as well as juggling other demands of the clinical training, was at times challenging. I have learnt to organise and prioritise the tasks, work under pressure, and draw on support networks to persevere and maintain passion for the project.

I believe that my skills in statistical analysis have improved greatly as a result of conducting this study. Learning about various parametric and non-parametric tests has helped me further develop skills required to critically evaluate published research and to use statistical methods in the future. The findings of the project were disseminated through written reports sent to the participants, the R&D and the ethics committee, as well as through presentations to the services. The process of writing up the findings has enabled me to develop skills in communicating research to different audiences and has given me a sense of satisfaction from accomplishing a task that contributes to knowledge in the area. I have become fascinated by the complexity of the topics of emotion regulation as well as psychosomatic disorders, and I would like to continue to practise the skills that I have developed in this project by conducting further research in these areas. It is my intention to develop my skills in using qualitative methodologies in the future.

Question 2. If you were able to do this project again, what would you do differently and why?

Recruiting participants for the PNES group was both a rewarding and challenging part of the project. Over the course of the final year of training, I approached 181 patients and received 56 responses, yielding the response rate of 31%. Although this response rate is typical of this type of research, the data collection phase was slow and time-consuming and until the last couple of months before the submission date, it was uncertain whether I would be able to recruit a sufficient number of participants to write up the thesis on time. Whilst I enjoyed the sense of being in control, associated with carrying out a project that I had designed and implemented, not being part of the team where I was recruiting posed challenges. For instance, it was at times difficult to motivate members of the clinical teams to suggest potential participants for my project. On reflection, perhaps I could have arranged more regular face-to-face meetings to discuss the recruitment and progress of the project, particularly with senior clinicians in the team. If I was to carry out this project again, I would allow more time to collect data from PNES patients. Nevertheless, I feel that the process of data collection has helped me further develop communication and assertiveness skills. It also made me reflect on the value of research teams, and the importance of promoting the ethos of research in services.

Initially, I planned to match the two groups of participants on the basis of gender and age. With this goal in mind, I recruited nearly three times as many participants for the control group, but this was not sufficient to carry out the matching procedure. Although the lack of matched samples was a limitation of the study, some of the variables were controlled for in the analysis. I also think it would have been beneficial to recruit a clinical comparison group, e.g. people experiencing anxiety disorder, borderline personality disorder or epilepsy. However, given the time frame of the study and the limited time for the project, I had to take

a pragmatic decision and recruit a healthy control group in the first instance, with the possibility of recruiting a clinical control group at a later stage.

Emotion regulation is becoming a popular and a fast-moving field of research. When I was designing my research project and reviewing the existing literature, none of the studies specifically examined emotion regulation in PNES. During the course of carrying out this research, two relevant studies of emotion regulation in PNES population were published (Roberts et al., 2012; Uliaszek, Prensky & Baslet, 2012). Whilst it was somewhat disappointing that I was not able to adjust my project in the light of their findings, it confirmed that there was a clear gap in the literature and it validated my interest in the area. On reflection, it might have been beneficial to use measures distinguishing between positive and negative emotions and to perhaps collect more data regarding heterogeneity of the PNES group. For instance, it might have been relevant to include a measure of trauma, as it has been associated with emotion regulation difficulties (Aldao, Nolen-Hoeksema, & Schweizer, 2010) and alexithymia (Taylor, 2010; Zeitlin, McNally, & Cassidy, 1993). This would be an interesting focus for future research, as it may contribute to our understanding of the aetiology of emotion regulation difficulties in PNES.

Question 3. Clinically, as a consequence of doing this study, would you do anything differently and why?

I have not had any prior experience of working with people, who had PNES and my knowledge about this condition has developed greatly, as a result of conducting this study. I have learnt that the issue of diagnosis is an important and sensitive one. The diagnostic process is complex and many patients are treated for epilepsy for several years before they find out that their seizures are non-epileptic. The shift from the diagnosis of epilepsy to PNES can be particularly difficult for some people. Many patients experience the diagnosis of PNES

as blaming and invalidating, and it takes time to adjust to a different way of understanding their difficulties. Several participants that I contacted with regards to taking part in this research said that the subject of their diagnosis was still ‘raw’ and they did not wish to engage in the project because of it. Therefore, I would be sensitive to this issue when working with PNES patients and I would consider offering support with the adjustment to the diagnosis as part of my practice. Through my experiences of conducting this study, I have become aware of a strong need for a range of psychological interventions, such as psycho-education, support groups, as well as individual, group and family therapy. Interventions should be offered at different levels to respond to heterogeneous needs of people with PNES.

Emotion regulation is an appealing and a challenging construct, which cuts across diagnostic boundaries and is pertinent to many forms of psychological distress. In my clinical work, I have become more aware of my clients’ beliefs about emotions, their ability to identify and describe feelings and how these aspects affect the way they manage stressful situations. I have become interested in ways in which people avoid painful events, which are both external and internal, and how this can lead to emotional distress. There is a growing body of evidence suggesting that addressing emotion regulation processes in therapy, e.g. building up skills in somatic awareness, developing regulation skills, improving distress tolerance, activating and exploring the meaning of specific emotions in therapeutic setting are important for therapeutic change (Whelton, 2004). I am hoping to incorporate approaches that specifically address emotion regulation difficulties into my clinical work and to pursue further training in Dialectical Behaviour Therapy (Linehan, 1993), Acceptance and Commitment Therapy (Hayes, Luoma, Bond, Masuda & Lillis, 2006) or Emotion Regulation Therapy (Mennin, 2004).

Question 4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

Research in the area of emotion regulation in PNES is still in its infancy and many questions remain unanswered. As mentioned above, future studies need to differentiate between regulation of positive and negative emotions in PNES and to explore the aetiology of the emotion regulation difficulties in PNES. Moreover, there is a paucity of data on subjective experience of emotions in PNES. Qualitative interviews could be used to explore experiences of and beliefs about different emotions and their management in PNES patients. This research may also be helpful in establishing particular research questions that can then be addressed using experimental methods.

Further to this, whilst the current findings suggest that the ability to recognise and regulate one's own emotions is impaired in PNES, there is a paucity of studies examining the ability to recognise and regulate emotions in others. It would be an important aim for future research, as poor emotion recognition and regulation in self and others could underpin the difficulties with relationships, previously reported in the PNES literature (Holman, Kirkby, Duncan & Brown, 2008; Moore, Baker, McDade, Chadwick & Brown, 1994; Wood, McDaniel, Burchfiel & Erba, 1998). The concept of mentalisation might be helpful in guiding this research (Bateman & Fonagy, 2004), as it refers to the capacity for awareness and emotion regulation in oneself and others. The study could examine PNES patients' ability to read body language and ability to understand cognitive and affective states of self and others, compared to patients with borderline personality disorder and healthy controls, using some experimental methods, such as the Perspectives Task (Dumontheil, Apperly, & Blakemore, 2010), the Movie for Assessing Social Cognition (Dziobek et al., 2006), the Mind in the Eyes (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) or the Level of Emotional Awareness Scale (Lane, Quinlan, Schwartz, Walker, & Zeitlin, 1990).

Furthermore, the role of attachment relationships needs to be explored further in the PNES population. This research could employ Adult Attachment Interview (George, Kaplan & Main, 1985) to examine specific distribution of attachment patterns in the PNES group, compared to the control group. Further to this, it would be helpful to know how the attachment styles link to the emotion regulation styles in PNES.

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Section D: Appendices of Supporting Material

Appendix A

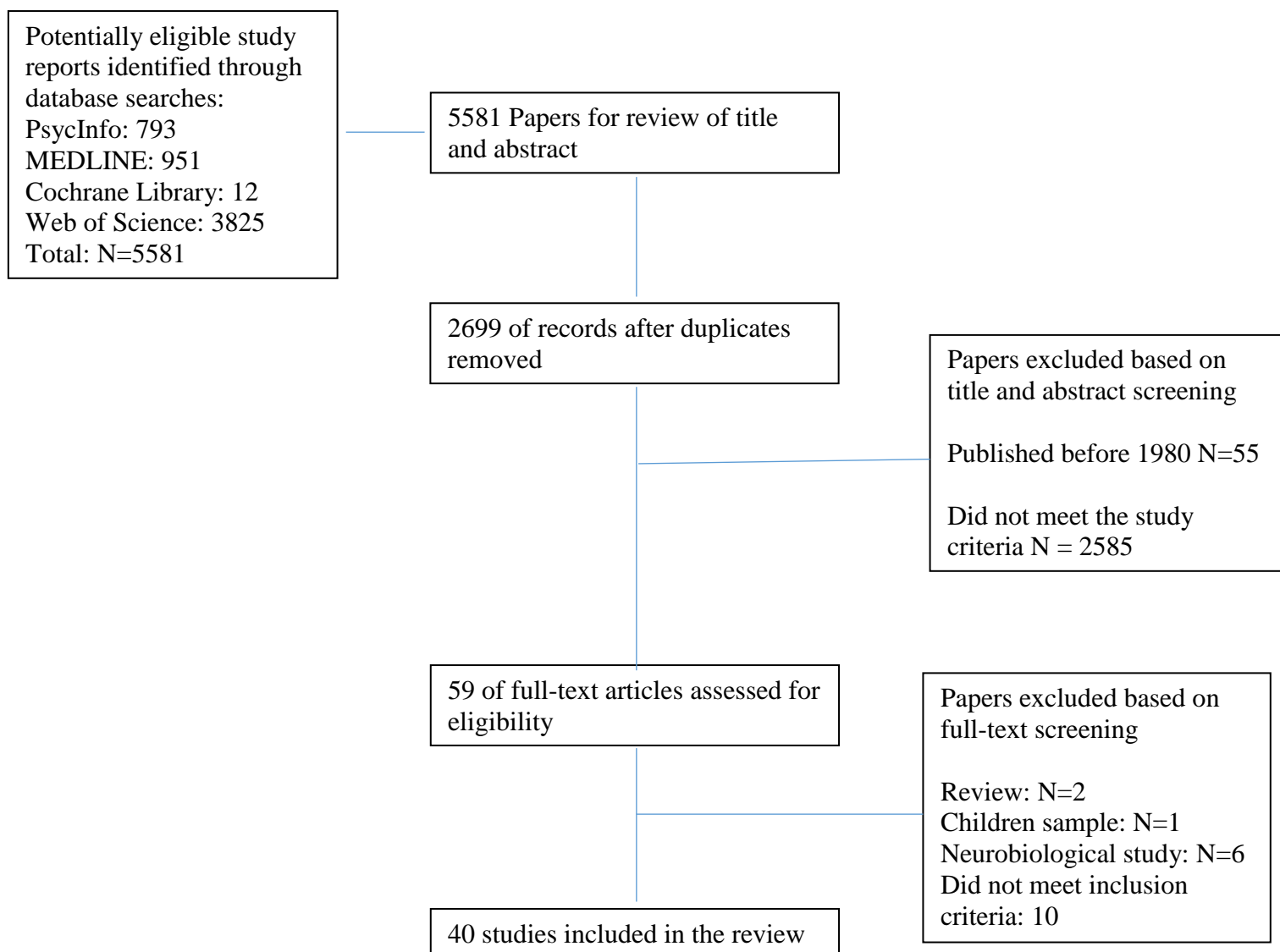
Literature search strategy

A literature search was conducted in March 2013, using the following electronic databases: PsycINFO, Medline, Cochrane, and Web of Science (Table 1). Articles were identified by using the terms: ‘non-epileptic seizures’; ‘psychogenic seizures’; ‘dissociative seizures’; ‘hysterical seizures’; ‘pseudoepileptic seizures’; ‘pseudoseizures’; ‘functional non-epileptic attacks’; and ‘non-epileptic attack disorder’. From the combined lists thus obtained, duplicates were eliminated. Titles and abstracts were screened using the following key words: ‘affect regulation’, ‘coping’, ‘mood’, ‘emotion’, ‘emotion regulation’, ‘alexithymia’, ‘dissociation’, ‘somatisation’ and ‘defence mechanisms’. Abstracts of articles were screened for relevance and if found to be applicable, the full article was retrieved. The internet searches using Google Scholar and manual searches of reference sections were also carried out to ensure that a comprehensive review of available literature.

This review focused upon literature published after 1980 (32 years) in peer reviewed journals. Studies examining aspects of affect regulation as defined by the key words, in patients diagnosed with PNES were included. The following exclusions were used: dissertations, commentaries, review articles with no original data, case studies, books, non-English language articles, opinion papers and responses. Studies of children and adolescents as well as people with learning disabilities were also excluded. As the main focus of this review was on psychological aspects of affect regulation, studies with neurobiological data only were excluded from the review (for a recent review of neurobiological literature, see Dickinson & Looper, 2012). A total of 40 studies were identified (Figure 1.). Articles were fully reviewed with the aim of extracting information relevant to affect regulation in PNES.

Table 1. Number of articles identified

	PsycInfo	Medline	Cochrane	Web of Science
Nonepileptic seizures	383	384	1	1,287
Psychogenic seizures	141	182	1	1253
Dissociative seizures	12	8	4	185
Hysterical seizures	35	38	2	163
Pseudoepileptic seizures	19	37	0	102
Pseudoseizures	187	274	3	732
Functional non-epileptic attacks	0	0	0	11
Non-epileptic attack disorder	16	28	1	92
Total	793	951	12	3,825

**Figure 1.** Flow chart of the process of literature search

Appendix B

Approval Letter from the NHS Ethics Committee

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Appendix C

Approval Letter from the R&D Department 1

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Appendix D

Approval Letter from the R&D Department 2

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Appendix E
Approval Emails from the University

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Appendix F

Consent form

[NHS Trust Logo]

[NHS Trust Logo]



Title of the project: Emotional regulation of individuals with
non-epileptic seizures

Name of Researcher: Monika Urbanek

Please put your initials in each box.

I have read and understood the information sheet dated 11.10.2012 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I have the right to withdraw from the project at any time without giving any reason and without my medical care being affected.

☐

I understand that all data collected about me will be kept strictly confidential and will not be identifiable as my own.

☐

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

☐

I agree to take part in the above study.

☐

Name of ParticipantDate.....

Signature

Name of Person taking consent:.....Date.....

Signature

Appendix G

Participant Information Sheet for Patients

[NHS Trust Logo]

[NHS Trust Logo]



Participant Information Sheet

Hello. My name is Monika Urbanek and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. You can talk to your family, friends, doctors or nurses about this study if you want to.

What is the purpose of the research study?

A broad aim of this study is to explore how people diagnosed with non-epileptic seizures think about their emotions and what they do to make themselves feel better. Greater knowledge in this area will help to understand the condition and improve treatment for people with non-epileptic seizures.

Who is organising and funding the research?

This research project is being undertaken as part of the requirement of a Doctoral Programme in Clinical Psychology at Canterbury Christ Church University, with Monika Urbanek as the principal investigator, and Dr XXXXX (XXXXX Trust), Dr XXXXX (XXXXXXX Trust) and Dr XXXXX (Canterbury Christ Church University) as the research supervisors. This project is funded by Canterbury Christ Church University.

Why have I been chosen to take part?

You have been chosen to take part because you have a diagnosis of non-epileptic seizures. In total, 130 participants will take part in this study.

Do I have to take part?

It is up to you to decide to join the study. If you decide to take part you may withdraw your consent to further involvement in the research at any time without giving a reason. Your access to health care will not be affected if you do not want to take part in the study or if you withdraw from the study.

What will happen if I decide to take part?

If you decide to take part, you will be asked to complete the consent form and five questionnaires, with multiple choice questions, looking at the different ways that people can experience and manage their pleasant and unpleasant emotions. It should not take more than 30 to 40 minutes to complete all of the questionnaires. The questionnaires can be completed in the clinic or posted to you.

What are the possible disadvantages of taking part?

Some people might find that answering questions regarding their experiences of some emotions or ways of managing them might cause some distress or discomfort. If you find it difficult and upsetting to complete the questionnaires, you can stop at any time.

What are the benefits of taking part?

Your experience will be used to expand our understanding of the phenomenon of non-epileptic seizures and potential processes that could be contributing to these symptoms. The findings might lead to further research in the area and advancement in treatment of non-epileptic seizures.

If you are interested, your name will be entered into a draw and you will have a chance to win an Amazon voucher, worth £70, £20 or £10.

Will my participation in this study be kept confidential?

All data and personal information will be stored securely within Canterbury Christ Church University premises in accordance with the Data Protection Act 1998 and the University's own data protection requirements. All information collected about you during the course of the research will be kept strictly confidential, and documents will be stored securely on a CD in a locked cabinet. Your answers will not be linked directly to your name. Your GP will need to be informed about your decision to take part in the study, but s/he will not have access to your answers. Data can only be accessed by the principal researcher and the supervisors, listed in the initial paragraph of this sheet. The collected data will be used for statistical analysis, the results of which might be published in the future. You will, however, not be identified in any publication. The documents will be disposed of securely after 10 years. If you are interested in a summary of findings of this research, please let us know.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your safety and well-being. This study has been reviewed and given favourable opinion by the City Road and Hampstead Research Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, please contact me and I will do my best to answer your questions (mu28@canterbury.ac.uk or 01892 50 7673). If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director on (44) 01892 507 773.

Who do I contact if I need more information?

If there is anything that is not clear, or if you would like more information regarding this study, please feel free to contact me at mu28@canterbury.ac.uk or 01892 50 7673.

You can also seek general advice about taking part in research from the Patient Advice and Liaison Service: [Email] [Phone number] [Address]

What if I want to take part?

If you want to take part in the study, you can complete the questionnaires and return them by post or we can arrange a convenient time to meet at the clinic to complete the questionnaires. If you have any questions about taking part in this study, please contact me on mu28@canterbury.ac.uk or 01892 50 7673.

Thank you for considering your participation in this study.

Appendix H

Participant Information for Healthy Control Group

Feelings matter

Welcome

Before taking part in this study, please read the information below.

What is this survey about?

- ♣ People experience, think about and manage emotions in different ways and you will be asked to answer a series of multiple-choice questions regarding your experiences of emotions, both pleasant and unpleasant.
- ♣ By taking part in this survey, you are helping to refine ways of working with people who may be distressed by their emotional reactions. Research in this area is also of great value to how we understand human experiences and emotional well being.
- ♣ Some people might find that answering questions regarding their experiences of some emotions or ways of managing them might cause some distress or discomfort. If you find it difficult and upsetting to answer questions in this survey, you can stop at any time.

Completing the survey

- ♣ There are no right or wrong answers. We are mostly interested in the pattern of your answers.
- ♣ Please only complete this survey once. It will take up to 20 minutes to complete.
- ♣ Please note that some questions may seem repetitive. This is deliberate and an important part of the research as we are comparing new questions to previous ones.
- ♣ Please read instructions carefully, as there will be different sets of instructions on each page.
- ♣ Participation is voluntary and you may withdraw from the study at any time. If you wish to do so, simply close this window.

Prize draw

- ♣ If you choose to do so, you may submit your email address for a chance to win an Amazon Voucher worth £70, £20 or £10.

Confidentiality

- ♣ All data collected about you will be kept strictly confidential and your responses to the questions will not be linked to your name. The collected data will be used for statistical analysis, the results of which might be published in the future. You will, however, not be identified in any publication.
- ♣ If you provide an email address, this will be stored separately from your data and will be permanently deleted once data have been collected and the vouchers have been claimed.
- ♣ Data collected in this survey will be stored securely on a CD in a locked cabinet and will be disposed of securely after 10 years.
- ♣ At the end of the survey, you will be asked to indicate whether you would like to be e mailed a summary report of the main findings.

What if there is a problem?

- ♣ If you have a concern about any aspect of this study, please contact me and I will do my best to answer your questions (mu28@canterbury.ac.uk or 01892 50 7673). If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director on (44) 01892 507 773.

Who do I contact if I need more information?

- ♣ If you have any questions about the study, please contact me on 01892 50 7673 or mu28@canterbury.ac.uk.

Please click continue if you understand the statements above and consent to participate in this study. If you do not wish to continue, simply close this window.

Appendix I
Invitation letter to Patients

[NHS Trust Logo]



[NHS Trust Logo]

Department of Applied Psychology
Canterbury Christ Church University
Broomhill Road
Tunbridge Wells, Kent
TN3 0TG

[Patient's Name]

[Address]

[Date]

Invitation to be part of a research study and an opportunity to win Amazon vouchers worth £70, £20 and £10.

Dear Mr/Mrs [Patient's Name],

My name is Monika Urbanek and I am a trainee clinical psychologist at Canterbury Christ Church University, working in collaboration with the Neuropsychiatry Services in XXXX and XXXXXX. I would like to invite you to take part in a research study investigating emotional well-being of people who experience non-epileptic seizures. This research project is being undertaken as part of the requirement of a Doctoral Programme in Clinical Psychology at Canterbury Christ Church University. Participation would involve completing questionnaires.

Please find enclosed an information sheet about this study. Please take time to read the enclosed information and discuss it with others if you wish. If there is anything that is unclear or if you would like more information, please contact me at mu28@canterbury.ac.uk or 01892 50 7673. If you would like to take part, please contact me via email or telephone. You can complete the questionnaires and send them by post or we can arrange a convenient time to meet. If I do not hear from you, you may receive a phone call from me in the next two weeks. It will be an opportunity to discuss the study and ask further questions. If you do not wish to receive this phone call and you do not wish to take part in this study, please inform me via email mu28@canterbury.ac.uk or telephone message (01892 50 7673).

Thank you for reading this.

Yours sincerely,

Monika Urbanek,

Trainee Clinical Psychologist

Appendix J

Invitation email to the Healthy Control Group Participants

Online research invitation and a chance to win Amazon vouchers worth £70, £20 and £10

Hello,

I would like to invite you to take part in an anonymous online study that I am conducting for my doctoral dissertation, looking at different ways that people can experience and manage their feelings. This research project has been given full ethical approval by the City Road and Hampstead Research Ethics Committee.

Participation involves completing an online survey, which takes up to 20 minutes.

If you are interested, you can enter a prize draw to have the chance of winning an Amazon voucher worth £70, £20 and £10.

For further information and to complete the online survey, please click on this link: <https://survey.canterbury.ac.uk/feelingsmatter>

If the link does not work, you can paste it into your browser instead. Please feel free to contact me at mu28@canterbury.ac.uk with any questions about this project.

Many thanks for your help,

Monika

Monika Urbanek
Trainee Clinical Psychologist
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Appendix K
Letter to Patient's GP

[NHS Trust Logo]

[NHS Trust Logo]



[Date]

Dear [GP's Name]
Re: [Patient's Name], [DOB]

I am writing to inform you that _____ has taken part in a research study investigating emotional well-being of people who experience non-epileptic seizures. A broad aim of this study is to explore how people diagnosed with non-epileptic seizures think about their emotions and what they do regulate their emotional states. Participation in this project involves completing five questionnaires. This research is being undertaken as part of the requirement of a Doctoral Programme in Clinical Psychology at Canterbury Christ Church University and has been approved by the City Road and Hampstead Research Ethics Committee.

Should you require further information, please do not hesitate to contact me at mu28@canterbury.ac.uk or 01892 50 7673.

Yours sincerely,

Monika Urbanek
Trainee Clinical Psychologist

Appendix L
Declaration of the End of a Study

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Appendix M

Letter to the NHS Ethics Committee regarding Research Findings

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Appendix N

Letter to the NHS R&D Department regarding Research Findings



Salomons Campus at Tunbridge Wells

Department of Applied Psychology
Canterbury Christ Church University
Runcie Court
David Salomons Estate
Broomhill Road
Tunbridge Wells
TN3 0TF

[Contact in Department]
[NHS Trust] Research & Development Department
[R&D Department Address]

[Date]

Study Title: **Regulation of emotions in individuals with nonepileptic seizures**
REC Reference: **12/LO/0473**

Dear [Contact],
Thank you for granting R&D approval for the above research project on 22 August 2012. I am writing to inform you that data collection for the study has now been completed. Please find attached a summary report of the research findings.

Please do not hesitate to contact me if you require any further information.

Yours sincerely,

Monika Urbanek
Trainee Clinical Psychologist
Mu28@canterbury.ac.uk

Appendix O

Report for Research Ethics Committee and R&D Departments

Research Summary

Title: Regulation of emotions in individuals with psychogenic non-epileptic seizures

Regulation of emotions in individuals with non-epileptic seizures

Researcher: Monika Urbanek, Trainee Clinical Psychologist.

Supervisors: Dr Martin Harvey, Dr John McGowan, Dr Niruj Agrawal.

REC Ref: 12/LO/0473

Background and research aims:

Whilst psychogenic non-epileptic seizures (PNES) superficially resemble epileptic seizures, they are thought to have a psychological origin and represent an experiential or behavioural response to emotional distress. Despite the long history of PNES relatively little is known about the mechanisms that cause and maintain this condition. Previous research has suggested that psychogenic non-epileptic seizures (PNES) might be associated with alexithymia, which can be defined as difficulties with identifying and describing feelings. Whilst emerging research evidence suggests that patients with PNES might have difficulties in regulating their emotions, much remains to be learned about the nature of these difficulties and the emotional responses of individuals with PNES.

The present study aimed to gain a detailed understanding of emotion regulation processes in patients with PNES, by examining differences between PNES patients and a control group with regards to intensity of emotional reactions, understanding of one's emotional experience, beliefs about emotions and control of emotional expression. The study sought to investigate whether these aspects of emotion regulation could be used to predict whether a person was likely to have PNES or not. Finally, the goal was to examine whether there was a relationship between emotion regulation difficulties and seizure characteristics (frequency, severity, bothersomeness).

Design:

This study adopted a quantitative, non-experimental, cross-sectional design.

Participants:

PNES group. PNES patients were recruited from the Neuropsychiatry Services in two NHS Trusts in South East of England. A total of 56 individuals with a diagnosis of PNES took part in the study, with a mean age of 39.2 years ($SD=13.60$, range 18 to 71). There was a significant variability in the frequency and severity of seizures experienced by participants in the PNES group.

Healthy control group. The control group was recruited through a university and social networking sites. A total of 88 participants comprised a final sample, with a mean age of 27.2 years ($SD=9.32$, range 18 to 56).

Procedure:

Participants completed four questionnaires, measuring aspects of emotion regulation, namely the intensity of emotions, the understanding of one's own emotional experience, the beliefs

about emotions and the emotional control. Another questionnaire examined levels of anxiety and depression in the samples. The total scores and total subscale scores were computed for each questionnaire.

Findings:

- Results showed that PNES patients did not experience more intense emotions than participants in the control group.
- However, PNES patients experienced more difficulties with identifying feelings, describing feelings and externally oriented thinking. They also had more negative beliefs about their emotions overall, and were more likely to think that their emotions were overwhelming, shameful, useless, damaging and contagious.
- 63% of the participants with the diagnosis of PNES, compared to 14% of participants in the control group, classified in the clinical range for alexithymia. This difference was statistically significant.
- In addition, alexithymia and negative beliefs about emotions were found to be significant predictors of PNES, even when age, education level and emotional distress were controlled for.
- PNES group showed significantly higher level of emotional control, particularly with regards to anxiety and sadness, compared to the control group. However, emotional control was not found to be a significant predictor of PNES.
- The results also showed that participants with more difficulties in emotion regulation, experienced more symptoms of anxiety and depression. Furthermore, there were significant associations between high scores on alexithymia and negative beliefs about emotions with ratings of seizures as ‘severe’.

Conclusions:

In conclusion, the results of the present study suggest that emotion regulation processes might be an important factor in PNES. PNES patients reported significantly poorer understanding of their emotions, more negative beliefs about emotions and higher use of emotional control strategies. These results are largely consistent with previous literature and highlight the importance of considering emotion regulation difficulties in psychological formulation and treatment of PNES. However, it is worth noting that patients with PNES are a very diverse group, with different histories and therefore these findings might not be relevant to all patients experiencing these types of seizures. Further research is required to replicate current findings before more definite conclusions can be drawn, and to advance our understanding of the complex emotion regulation processes in the PNES population.

Appendix P
Letter and Report for Participants



Department of Applied Psychology
Canterbury Christ Church University
Runcie Court
David Salomons Estate
Broomhill Road
Tunbridge Wells
TN3 0TF

[Participant's name]
[Participant's address]

[Date]

Dear Mr/Mrs [Participant surname]

Re. Feedback from the research project, entitled 'Regulation of emotions in individuals with non-epileptic seizures'

I am writing to let you know that I have recently completed this research project. I would like to thank you for taking part. I very much appreciated and valued your contribution to this study. You indicated that you would like to receive a summary of the research findings and therefore I have enclosed the final report with this letter. This report outlines how the data collected through the questionnaires were analysed and what the findings were. I hope you find this helpful.

I would like to wish you the very best for the future.

Yours sincerely,

Monika Urbanek

Trainee Clinical Psychologist

Research Summary

Title: Regulation of emotions in individuals with non-epileptic seizures

Researcher: Monika Urbanek, Trainee Clinical Psychologist.

Supervisors: Dr Martin Harvey, Dr John McGowan and Dr Niruj Agrawal.

Aims of the study:

Previous research has suggested that psychogenic non-epileptic seizures (PNES) might be linked to emotional distress and difficulties with identifying and describing feelings. I was interested in emotional well-being of people with PNES and wanted to investigate how people with a diagnosis of PNES manage their feelings. More specifically, I was interested in examining intensity of feelings, ability to understand one's own feelings, beliefs about emotions, and strategies people use to manage their emotions, e.g. bottling feelings up. My aim was to find out if these aspects of emotional functioning could be used to predict whether a person was likely to have PNES or not. Finally, I also wanted to examine whether there was a relationship between emotion regulation difficulties and frequency, severity and bothersomeness of seizures.

Participants:

All together, 145 people took part in this study, 56 people had a diagnosis of non-epileptic seizures and 88 were participants, who did not have seizures or any other major underlying health or mental health problems (the 'control' group). Everyone was asked the same questions and completed the same questionnaires. My aim was to compare the scores from participants with PNES with those, who did not have PNES, to identify if there were any differences between the groups.

Analysis of responses:

The questionnaires you completed, contained questions about four broad areas of emotional functioning, namely the intensity of emotions, the understanding of one's own emotional experience, the beliefs about emotions and the control of emotional responses, including anxiety, depression and anger. You also completed a questionnaire, measuring symptoms of anxiety and depression.

I added up the scores on the questionnaires to get a total score for each participant and entered them into statistical software in order to carry out the analysis. The statistical tests that I used were based on everyone's total scores, considered together. This means that your own experience may not be the same as the results that are described below, as the findings were based on an average for the whole group. Please be assured that your responses were included in the analyses.

Findings:

- Results showed that people with PNES did not report experiencing more intense emotions than those, who did not have PNES ('control group').
- PNES patients experienced more difficulties with identifying their feelings and describing their feelings than the control group. They also had more negative beliefs about their emotions, and were more likely to think that their emotions were overwhelming, shameful, useless, damaging and contagious.
- 14% of participants in the control group and 63% of the participants with the diagnosis of PNES could classify as having alexithymia, which can be described as a difficulty with identifying and describing feelings.
- There was also a difference in the way participants with PNES managed their feelings, as they seemed to control the expression of their emotions of worry and sadness more than the participants in the control group. In other words, they were more likely to 'bottle up' some of their feelings.
- The results also showed that those participants, who had very negative beliefs about their feelings, experienced more symptoms of anxiety and depression. They were also more likely to rate their seizures as 'severe'. Frequency of seizures was not associated with the measured aspects of emotion regulation.

As the research on this topic is still in the early stages, these findings are important. They highlight specific difficulties that might be relevant for some people experiencing PNES. This is of significance, as these areas might be used to inform psychological treatments of PNES. However, it is worth noting that patients with PNES are a very diverse group, with different histories and therefore these findings might not be relevant to all patients experiencing these types of seizures. Further research will need to be carried out before we can be more certain about these findings, and before definite conclusions can be drawn.

Appendix Q
Demographic Questionnaire: Patient Group



DEMOGRAPHIC QUESTIONNAIRE

Age					
Gender:	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20%;">Male</td> <td style="width: 20%;"></td> <td style="width: 20%;">Female</td> <td style="width: 20%;"></td> </tr> </table>	Male		Female	
Male		Female			

Ethnicity:			
White		Black or Black British	
British		Caribbean	
Irish		African	
Any other White		Any other Black background	
Asian or Asian British		Mixed	
Indian		White and Black Caribbean	
Pakistani		White and Black African	
Bangladeshi		White and Asian	
Any other Asian		Any other Mixed background	
Chinese			
Other (please specify)			
Prefer not to state			

What is the highest level of education you have completed? (Check one box)

Primary school	
Secondary school	
O levels/GCSEs	
A levels	
Technical or Trade Certificate	
Diploma	
Degree	
Postgraduate Degree	

Appendix R
Demographic Questionnaire: Healthy Control Group



DEMOGRAPHIC QUESTIONNAIRE

Age			
Gender:	Male		Female

Ethnicity:			
White		Black or Black British	
British		Caribbean	
Irish		African	
Any other White background		Any other Black background	
Asian or Asian British		Mixed	
Indian		White and Black Caribbean	
Pakistani		White and Black African	
Bangladeshi		White and Asian	
Any other Asian background		Any other Mixed background	
Chinese			
Other (please specify)_____			
Prefer not to state			

What is the highest level of education you have completed? (Check one box)

Primary school	
Secondary school	
O levels/GCSEs	
A levels	
Technical or Trade Certificate	
Diploma	
Degree	
Postgraduate Degree	

Do you have a history of any of the following? YES OR NO ANSWERS to all

epileptic seizures	YES / NO	non-epileptic seizures	YES / NO
abnormal pregnancy/problems at birth	YES / NO	brain tumour	YES / NO
head injury	YES / NO	cancer	YES / NO
schizophrenia	YES / NO	stroke	YES / NO
personality disorder	YES / NO	self-harm	YES / NO
autism or autistic spectrum disorder	YES / NO	bipolar disorder	YES / NO
History of any other chronic medical condition: please specify.....	YES / NO	Are you currently diagnosed with any other illness? please specify.....	YES / NO

Appendix S

Affect Intensity Measure (AIM; Larson & Diener, 1987)

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Appendix T

The Toronto Alexithymia Scale-20 (TAS-20; Bagby, Parker, et al., 1994)

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Appendix U

Beliefs about Emotions Questionnaire (BAEQ; Manser, Cooper & Trefusis, 2012)

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Appendix V

Courtauld Emotional Control Scale (CECS; Watson & Greer, 1983)

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Appendix W

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

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Appendix X

Examination of Normality of Data

The distributions for each variable for each group of participants were examined using histograms, q-q plots and Kolmogorov-Smirnov test scores. The results of the tests are presented below (Table 1). Significant scores on the test indicated a significant difference between the distribution of the sample and a normal distribution.

Table 1. Kolmogorov Smirnov Tests of Normality: Psychological Variables

Variable	Group	Kolmogorov-Smirnov		
		Statistic	df	Sig.
AIM TOTAL	Clinical	0.068	56	0.2
	Non-clinical	0.075	88	0.2
TAS TOTAL	Clinical	0.05	56	0.2
	Non-clinical	0.111	88	.010*
TAS DIF Total	Clinical	0.078	56	0.2
	Non-clinical	0.124	88	.002*
TAS DDF Total	Clinical	0.123	56	.035*
	Non-clinical	0.133	88	.001*
TAS Ext Total	Clinical	0.099	56	0.2
	Non-clinical	0.117	88	.005*
BAEQ TOTAL	Clinical	0.057	56	0.2
	Non-clinical	0.069	88	0.2
BAEQ Overwhelming	Clinical	0.109	56	0.092
	Non-clinical	0.081	88	0.2
BAEQ Shame	Clinical	0.12	56	.043*
	Non-clinical	0.125	88	.002*
BAEQ Invalid	Clinical	0.106	56	0.176
	Non-clinical	0.109	88	.012*
BAEQ Useless	Clinical	0.166	56	.001*
	Non-clinical	0.075	88	0.2
BAEQ Damaging	Clinical	0.1	56	0.2
	Non-clinical	0.081	88	0.2
BAEQ Contagious	Clinical	0.104	56	0.198
	Non-clinical	0.144	88	.000*
CECSTOTAL	Clinical	0.068	56	0.2
	Non-clinical	0.101	88	.026*
CECS Angry	Clinical	0.072	56	0.2
	Non-clinical	0.098	88	.037*
CECS Anxiety	Clinical	0.09	56	0.2
	Non-clinical	0.16	88	.000*
CECS Sad	Clinical	0.119	56	.045*
	Non-clinical	0.141	88	.000*
HADSTOTAL	Clinical	0.148	56	.004*
	Non-clinical	0.098	88	.037*
HADS Anxiety	Clinical	0.081	56	0.2
	Non-clinical	0.113	88	.008*
HADS Depression	Clinical	0.138	56	.010*
	Non-clinical	0.167	88	.000*

*p < .05

These results were compared with histograms, and q-q plots. Examples of histograms are presented below (Figure 1; Figure 2).

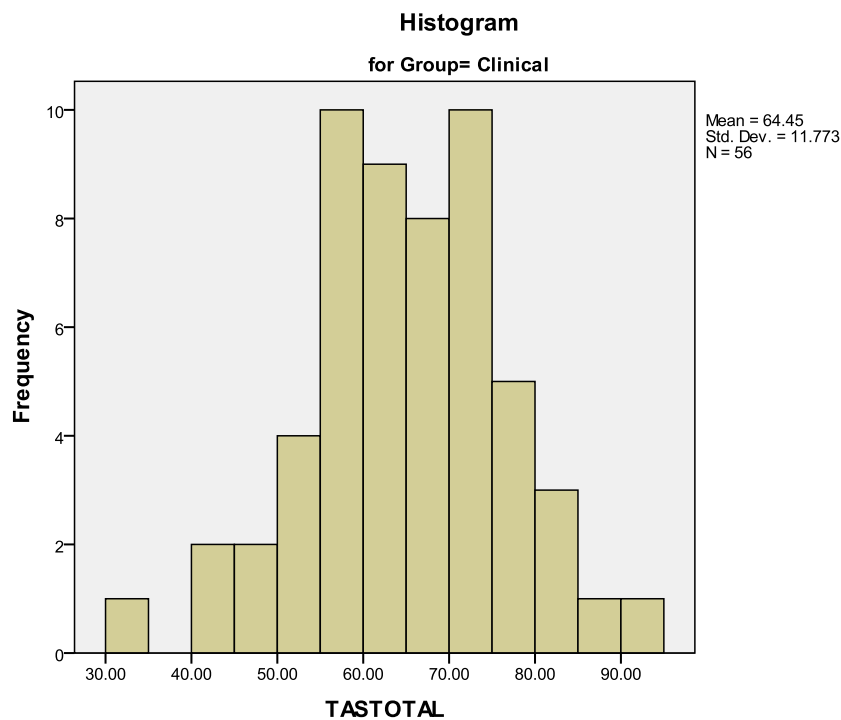


Figure 1. Histogram of the TAS-20 total scores for the PNES group.

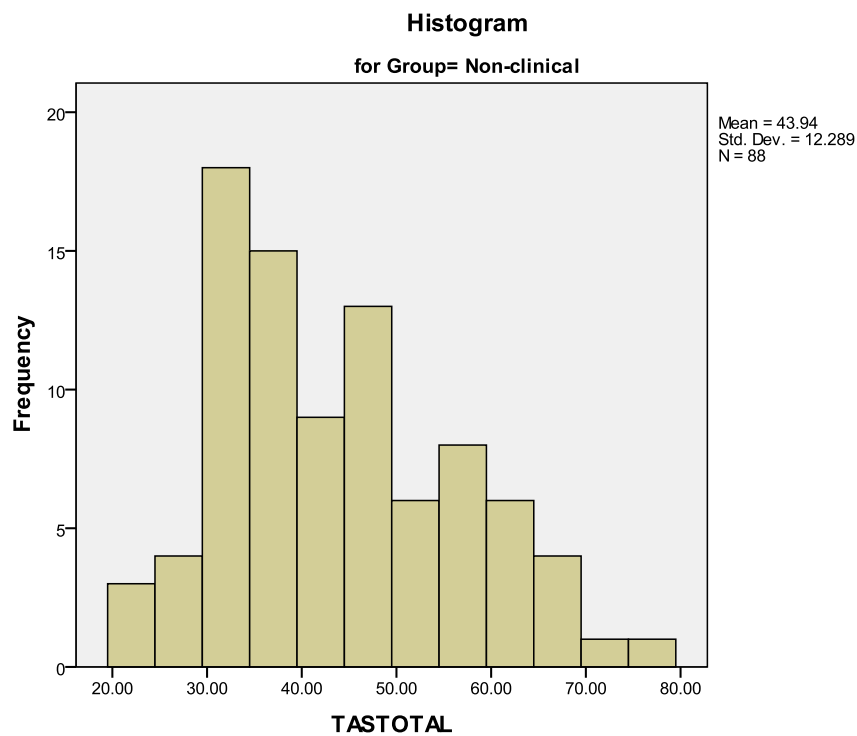


Figure 2. Histogram of the TAS-20 total scores for the control group.

Further examination of data showed that the seizure variables did not meet the assumption of normal distribution (Table 2.). An example of the histogram demonstrating a negatively skewed distribution for the seizure bothersomeness variable is presented below (Figure 3.)

Table 2. Kolmogorov Smirnov Tests of Normality: Seizure Variables

Seizure characteristics	Kolmogorov-Smirnov		
	Statistic	df	Sig.
Seizure Frequency	.229	50	.000*
Seizure Severity	.132	50	.029*
Seizure Bothersomeness	.155	50	.004*

*p < .05

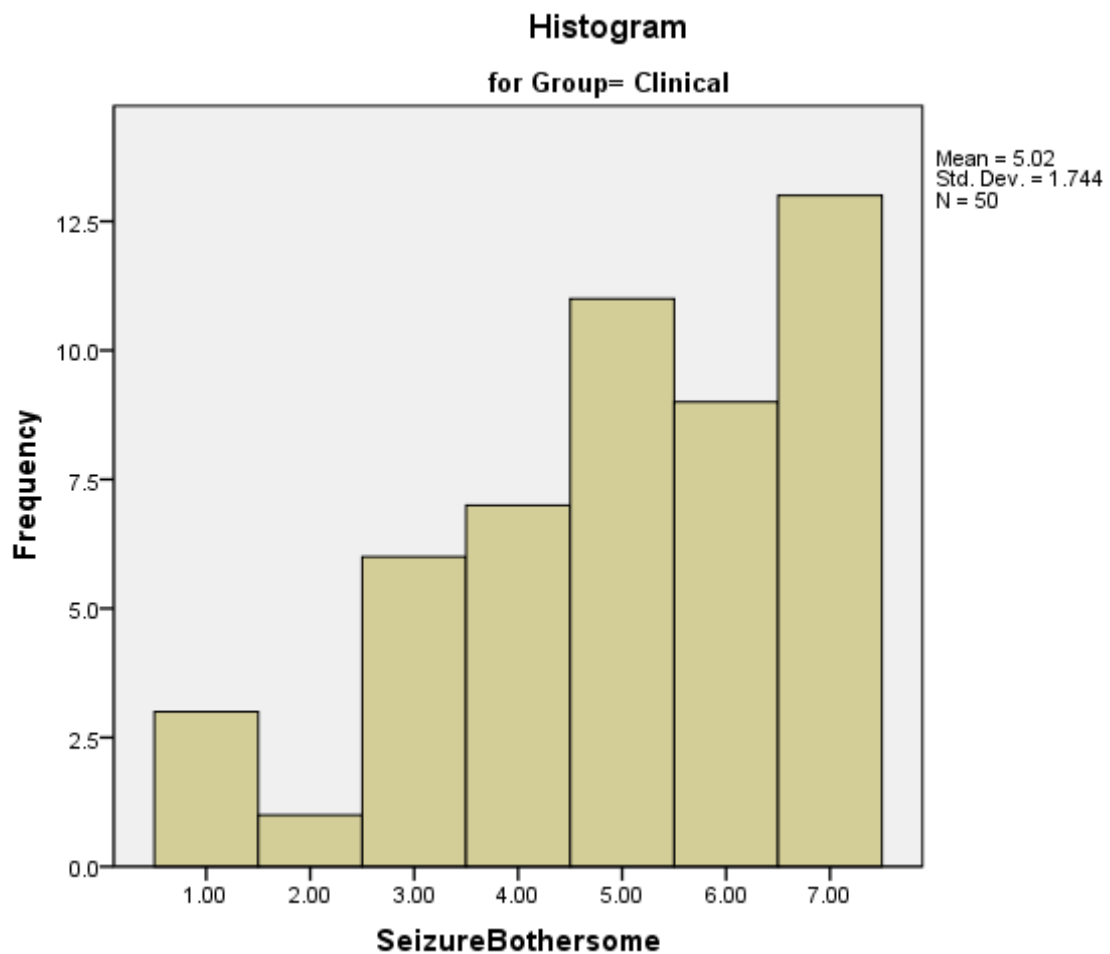


Figure 3. Histogram of the seizure bothersomeness scores for the PNES group.

Appendix Y

Submission Guidelines for Journal of Neuropsychology

Journal of Neuropsychology

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Author Guidelines

The Journal of Neuropsychology publishes theory-driven patient studies. The central brief is to learn more from patients with brain dysfunctions to gain a better understanding of brain-behaviour relationships and to help future patients. Important developments in neuropsychology will follow from a multidisciplinary approach embracing neighbouring fields such as developmental psychology, neurology, psychiatry, physiology, endocrinology, pharmacology and imaging science. The journal publishes group and case studies addressing fundamental issues concerning the cognitive architecture of the brain. In addition, the journal includes theory-driven studies regarding the epidemiology of specific deficits, new assessment tools, and the evaluation of treatment regimes.

The journal is committed to a fast and efficient turn-around of papers, aiming to complete reviewing in under 90 days. Submissions are processed via a web-based system and reviewers are required to complete their referee report within 28 days. Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

1. Quality Control

The content, format, quality and ambition of the JNP as a major outlet for theory-driven neuropsychological studies is under constant review by the Consulting Editors:

- Kenneth M. Heilman (University of Florida College of Medicine, Gainesville, USA)
- Donald T. Stuss (Rotman Research Institute, Baycrest, University of Toronto, Canada)
- Giuseppe Vallar (University of Milan-Bicocca, Italy)
- Elizabeth Warrington (National Hospital for Neurology and Neurosurgery, London, UK)

2. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

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Research papers are full-length reports of original scientific investigations. Papers should normally be no more than 6000 words excluding abstract (maximum 250 words) and references. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. The Editor retains discretion to publish longer papers.

Theoretical or review articles are full-length reviews of, or opinion statements regarding, the literature in a specific scientific area. They need not be exhaustive but should give an interpretation of the state of research in a given field. They should

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Special issues may be proposed to the Editor. The proposal should include a short description of the topic and a number of (possible) contributors. The same quality criteria apply as for other submissions.

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