

Understandings of Psychogenic non-epileptic seizures and their treatment.

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Health professionals have understood since Egyptian times that the human body can display what appear to be symptoms of illness, in the absence of organic causes. Until the twentieth century these symptoms were mostly commonly called Hysteria.

They are now referred to as either conversion or somatoform dissociation. Conversion is the term originally used by Freud and Breuer, around 1890, to refer to the conversion of psychological distress into bodily manifestations . This understanding was adopted by the American Psychiatric Association for their Diagnostic and Statistical Manual of mental disorders. The term dissociation originated with Pierre Janet's concept of disaggregation, around the same time. He understood these symptoms to result from a failure to integrate the various sensory, cognitive, and affective aspects of an experience into a person's sense of themselves. Janet's understanding informed the ICD classification system developed by the World Health organisation.

The term Somatoform dissociation refers to when there is an integrative failure that involves the sensorimotor components of an experience. Symptoms that can result include: paralyses; heart palpitations; disturbances of vision, hearing, speech, sensation and breathing; tics; somnambulism; catatonias; and seizure like states that have no underlying medical cause.

Because there is a growing body of evidence that dissociative processes underpin conversion and somatoform symptoms, although these processes are as yet poorly defined, in the Janetian tradition I will be using the term somatoform symptoms.

There are good reasons to improve our understanding and treatment of somatoform symptoms

The first concerns their cost in terms of scarce medical resources. Thirty to sixty per cent of patients in primary care settings complain of symptoms for which no medical basis is found.

Somatizing patients are frequent users of outpatients, general practitioners, and specialists. They are the most frequent users of unwarranted medications, for no change in condition. The few treatment/cost analyses that exist indicate that when they are properly diagnosed and treated, the saving in health resources is considerable. For instance these two Australian studies indicated that treating patients with BPD, a group in which somatoform symptoms are common, for 1 year using appropriate psychotherapy resulted in a saving to the health system in inpatient admissions alone of \$21,431 per patient (1999 dollars). These gains were maintained at 5 year follow up.

The average in patient admission time at 5 year follow up went from 2 months to zero days.

(Stevenson & Meares, 1999; Stevenson, Meares, & D'Angelo, 2005).

The second reason to come to a better understanding of somatoform symptoms is because they pose a considerable diagnostic challenge. The differentiation of somatoform symptoms from organic illness is time consuming and expensive because it involves the elimination of organic causes (Bowman & Markand, 2005). Diagnosis by elimination can result in misdiagnoses (Stone, et al., 2005) leading to unnecessary treatments with serious side effects (Oto, Russell, McGonigal, & Duncan, 2003; Reuber, Baker, Gill, Smith, & Chadwick, 2004). After a long search for physical causes, patients often find the diagnosis of a psychological disorder difficult to accept (Thompson, Osorio, & Hunter, 2005).

Finally, somatoform symptoms are of clinical interest because they have a high comorbidity with other psychiatric diagnoses including depression, anxiety, post traumatic stress disorder (PTSD),

borderline personality disorder and dissociative disorders (Bowman, 2001) and are associated with poor quality of life (Jones et al., 2010; Reuber, Mitchell, Howlett, & Elger, 2005).

The somatoform symptoms we chose to study are known as Psychogenic Non Epileptic Seizures (PNES). These consist of behaviours that look like seizures but differ from epilepsy and other medical events because they have psychological rather than medical causes. They are differentiated from epilepsy using video eeg monitoring of a typical range of seizure events.

PNES provide the ideal focus for understanding and treating a range of psychogenic symptoms for a number of reasons. First, relative to other psychogenic symptoms, they can be diagnosed with a high degree of certainty (Benbadis, O'Neill, Tatum, & Heriaud, 2005). Second, like many psychogenic symptoms, they are frequently misdiagnosed, resulting in delays in appropriate treatment, or they are treated inappropriately with drugs (Benbadis, 1999). This has adverse effects and results in misuse of scarce primary health care resources (Reuber, et al., 2004). Most importantly, as a high proportion of people with PNES also experience other psychogenic symptoms, the study of PNES provides a lens through which these complex reactions and their key psychological components can be explored (Bowman & Kanner, 2007).

Before we have a look at a piece of research that we have been conducting into Australian therapists understandings of PNES we will have a quick look at what research to date tells us about the factors that contribute to Psychogenic Seizures. The first contributing factor is Trauma. A history of physical, sexual and emotional trauma in childhood and across the life span is a well supported risk factor for psychogenic seizures, being found among 40-100% of people who experience PNES ( see Fiszman, Alves-Leon, Nunes, D'Andrea, & Figueira, 2004, for a review).

Recent advances in neurology have increased our understanding of how adverse early experiences influence the development of neurological pathways that underpin conversion and somatoform dissociation (Schoore, 1996)<sup>i</sup>. Reliance on primary care givers who are simultaneously a source of nurture and a threat to emotional, physical or sexual safety is a risk factor for forming and maintaining traumatising relationships later in life (Waldinger, et al., 2006). In turn, adult relational trauma is commonly associated with the onset of somatoform symptoms including PNES (Bowman & Markand, 1996, 1999; Harden, 2003) (Author, 2008). The correlation of trauma to psychogenic symptoms appears to be robust across cultures (see Sar, 2006, for a review). Extent and severity of childhood abuse correlates with complexity and severity of adult symptoms (Nijenhuis, Spinhoven, van Dyck, van der Hart, & Vanderlinden, 1998).

Somatoform symptoms appear more frequently when there has been a prolonged period of deprivation such as chronic sleep deprivation, exhaustion, cold, thirst, hunger, poor nutrition, lack of sanitation, exposure to high risk of disease and prolonged emotional strain (van der Hart, et al., 2000). Events which occur in these contexts are experienced as a shock. It is likely that during prolonged periods of deprivation and torment, such as war or natural disaster, resources must be directed towards survival, and are therefore not available for the integration of sensation, cognition, emotion and memory (van der Hart, Nijenhuis, Steele, & Brown, 2004; van der Hart, et al., 2000).

Somatoform symptoms also occur in people who have suffered loss following protracted emotional strain (Freud & Breuer, 1895, the case of Anna O.). Adolescents with their developing emotion regulation systems who are exposed to life stressors are also at increased risk of

somatoform symptoms such as PNES partly due to the anxiety that they experience as a result of the gap between the demands of the stressor and their developing self-resources (Witgert, Wheless, & Breier, 2004). Neurological events such as head injury and poorly controlled epilepsy are also highly correlated with PNES because of their ongoing or recurrent impact on the ability to maintain a coherent, consistent sense of self across time and place. They disturb memory, disrupt the integration of mind/body functions, raise distress levels and diminish distress tolerance skills, impinge on brain functions implicated in affect regulation, and diminish social value and self-worth (Breier et al., 1988; Kalogjera-Sackellares, 2004). It is noteworthy that these effects are similar to the psychiatric sequelae of attachment trauma discussed previously. These neurological disturbances are often chronic, reflecting damage to neurological systems underlying somatoform symptoms (Brown, 2002).

*Silencing expression of strong emotion.*

Contexts that restrict verbal expression of strong emotion and impose no-win choices seem to contribute to PNES (Griffith, Polles, & Griffith, 1998) (Author, 2010). The interpersonal dynamics in which childhood abuse most frequently occurs is one such context. It includes powerful incentives for perpetrators to silence victims to protect themselves from legal and social consequences (Herman, 2001). Victims are vulnerable to silencing because they must meet their need for safety, preserve relationships with carers and maintain a sense of self-worth, from within their family (Birrell & Freyd, 2006; Freyd, DePrince, & Zurbriggen, 2001; Herman, 2001). Together with the greater incidence of sexual abuse amongst females compared with males, this silencing provides one possible explanation for the greater incidence of trauma related psychogenic symptoms in females (McCloskey & Raphael, 2006).

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With these contributing factors in mind, and noting that PNES frequently present co-morbidly with a range of somatic and psychiatric conditions (Brown, Schrag, & Trimble, 2005), in patients with histories of attachment and recent trauma (Harden, 2003) we proposed that it may be clinically useful to conceptualize and treat PNES as part of a complex accommodation to trauma (Quinn, Schofield, & Middleton, 2008). We thought that an understanding of the role of dissociation in this accommodation might be central to treatment. We also thought that where there is brain injury or intractable epilepsy, it might also be clinically useful to view PNES as occurring in a context of continued interruptions to self. Knowing that PNES can occur in the absence of extensive co-morbidity, we suggested that PNES in these circumstances might be understood as a panic reaction in the context of under-developed affect regulation skills, social skills or social deprivation. We suggested that clear conceptualization, based on thorough assessment of co-morbidity and trauma history may provide clarity for treatment.

With these thoughts in mind in this study we interviewed therapists about their experiences of successfully treating clients with PNES. This study formed part of a larger qualitative research project that examined client and therapists' understandings of PNES and the process of their treatment. It was conducted with the approval of the Human Research Ethics Committee of La Trobe University, Melbourne, Australia.

### Method

A qualitative grounded theory approach was used to collect and analyze in-depth interview data. This means each interview was analyzed prior to conducting the next interview so that the analysis could inform the themes explored in the next interview. The interview data were

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analysed with the aim of constructing theory about useful understandings of PNES. Each interview took the form of a relatively open, unstructured discussion that also allowed the participant to introduce new themes. We then analysed data across themes to find the concept most central to the phenomena of therapists' understandings of PNES. Finally, we looked for how other concepts emerging from the analysis were related to this core concept.

Participation was invited from psychotherapists of any health profession who had treated a client with PNES in the last 5 years without recurrence of PNES in the past 12 months. There needed to be a record of the treatment process. The sample was identified through professional networks of the researchers and via a wide range of professional media between 2005 and 2010.

Verification of PNES by video-EEG was required. We attempted to recruit therapists working with clients with a range of co-morbidity profiles and trauma histories.

Participants were interviewed for 1-2 hours using open-ended interviews that were concerned with the professional background of the therapist and their understandings of PNES and their treatment. Therapists who had the written consent of a client were invited to refer in detail to their treatment. Participants were initially asked, "Could you tell me what you know about PNES and their treatment and how you came to that understanding?"

### Findings

Participants were 3 female and 5 male therapists. Seven participants were over 40 years of age and had over 15 years of experience in their profession. One was training in his profession. Seven participants had client consent to discuss their treatment; the other discussed his general understandings and experience of treating PNES.

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Participants' professional backgrounds included: 5 psychiatrists; (1 intern, 1 hospital based consultant/liaison psychiatrist, 3 private practitioners), 2 psychologists; (1 private practitioner, 1 employed by a non-government community based agency), 1 mental health nurse (private practitioner). Seven of the 8 participants had been treating the client they spoke of for between 2 and 13 years. The average length of therapy was 6.5 years, with 5 continuing in therapy.

The clients of this group of 7 participants were 2 males and 5 females, aged between 27 and 50. These clients had considerable psychiatric co-morbidity and complex trauma histories. Their diagnosed conditions co-morbid to PNES included epilepsy (2), Graves Disease (1), anxiety disorders (7), depression (4), dissociative identity disorder (DID) (3), borderline personality disorder (BPD) (3), Post traumatic stress disorder (PTSD) (5), dissociative disorder not otherwise specified (DDNOS) (2), somatoform disorder, conversion (2). The average number of co-morbid psychiatric conditions in clients described by these 7 participants was 3. Clients of these 7 participants had histories of multiple hospitalizations, extensive inpatient investigations, and multiple outpatient presentations for relief/treatment of these symptoms, prior to entering therapy. (Please note I have accidentally left PTSD off this slide)

One of our participants, working as a consultant liaison psychiatrist in a metropolitan hospital spoke about clients with PNES without extensive comorbidity or complex trauma histories. He conceptualised their PNES as arising out of immaturity, because they were adolescent, or lacking the social or personal skills to manage stress. He spoke of treating them with brief CBT based interventions that included psychoeducation, relaxation and stress management components

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aimed at empowering. He did not have scope to offer longer term interventions and spoke of referring out clients with more complex presentations.

The other 7 therapists spoke of their clients having acquired some norms of nonverbal communication of emotional distress in early attachments. Most described clients from families that were implicitly silencing. For instance one therapist noted of his client's upbringing:

*"I feel that culturally there may have been an inappropriate or unhelpful degree of religiosity in that early childhood period when his personality and reaction patterns were developing and I suspect that perhaps the message of "turn the other cheek" was taken too far."*

Some therapists described explicit silencing of traumatic affect by attachment figures. For instance, one therapist described her clients excommunication from her family as a child:

*"She slept outside in a shed, while her two older siblings slept with Mum and Dad inside . . . she was 'excommunicated' from the family and the church ...Dad held a bit of a kangaroo Court at home and formally excommunicated her in front of the family...". So the family was not allowed to talk to her."*

Therapist also described clients growing up in families that provided a non verbal model for the expression of emotion. In some cases these were understood by the therapist as providing a behavioural model for the PNES. For instance 3 therapists spoke of clients' families of origin practicing religious cleansings such as exorcisms and laying of hands during which seizure –like behaviours were witnessed or experienced.

Therapists with clients with complex presentations identified that some clients' PNES occurred when they were fully oriented to the present, when they were faced with situations that they did not have the skills to manage. They observed that these clients had difficulty managing inescapable conflict and regulating emotion. The clients they spoke of had diagnoses of BPD or had significant impairments to their sense of self, probably as a consequence of a form of

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emotional deprivation in early attachments. One therapist described the types of trauma that these clients suffered as:

*“difficult to recognise, the microscopic trauma, where there has often been a lack of recognition. There is a lack of connection”*

Therapists emphasised the importance of understanding the function that these clients’ PNES served. They noted that some PNES served the purpose of helping the client escape or leave a conflict. For instance the client I spoke of earlier from the religious back ground where he was encouraged to turn the other cheek. He was experiencing bullying at work. He was unskilled, had a mortgage and 3 children and could not leave work. At home his house adjoined the property of his wives relatives. His wife disclosed to him that one of these had sexually abused her as a child, but she swore him to secrecy. They had 3 young children. As his therapist put it:

*“His PNES are a way of coping . . he can’t physically escape so there has to be an excuse”*

The other purpose that PNES served for this group of clients with good orientation to the present was described by therapists as self harm. Although they used the words self harm therapists emphasised that, from the client’s point of view PNES gave them emotional relief. They emphasised that these clients were not aware of the long term harm of using PNES to relieve emotional distress. They were

fixated on the short term escape of unbearable emotion.

Therapists also spoke of clients whose PNES occurred when they were in states that were not oriented to the present. These clients had comorbid conditions characterised by such states, such as flashback states of PTSD, or the altered states of consciousness and ego states of DDNOS and DID.

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Again these PNES performed functions in these states of limited orientation to the present. One therapist with a client with PTSD described her PNES as re-enactment of her trauma, that she lacked the ability to describe verbally:

*“...she started developing pains in her lower back and buttocks and having PNES, and memories started to come back in little fragments starting with body feelings....Out of that came a strong reliving of after she was beaten and held up... by her arms by her mother, these are part of what happens sometimes in fits, a reliving... Bit by bit a sort of more narrative connect with it came.”*

Therapists described other PNES as ways of escaping. The difference for this group was that the escape was from an event that was not in the present. For instance a therapist whose client had DID described

*“...when she goes to sport with her son this part was having seizures because she thought that she was at the hockey field where she was also abused, instead of the soccer field 30 years later.”*

Other purposes served by PNEs when orientation to the present was lacking included protection from a perceived threat. For instance in a client with DID an introject of the abuser would inflict the seizure giving the client a sense of power or control over the original abuse. This also served the purpose of preserving the attachment to a perpetrating parent in parts of the self that were unaware that childhood was past.

Three therapists with clients with comorbid medical conditions that included seizures described occasions when their clients presented to hospital with seizures, at least some of which were thought to be medical, that probably resulted from missed medication. These therapists suggested that these seizures resulted from non-compliance with medication while in a state of limited orientation to the present.

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The understandings that therapists gained from their clients about early attachment trauma, silencing in early attachments, degree of orientation to the present during PNES and the purpose of each PNES, informed their therapeutic approach. Clients with good orientation to the present, limited dissociation but impaired self skills were effectively treated with therapies aimed at development of self, enhancing of emotion regulation, distress tolerance and interpersonal skills, especially those needed to address conflict.

Therapists treating clients with diagnoses characterised by impaired orientation to the present, such as PTSD, DID and DDNOS, made effective use of therapeutic approaches emphasising reorientation to a benign present. Provision of a safe therapeutic relationship was the cornerstone of this process of re acculturation. These therapists emphasised the importance of understanding the purpose of the PNES in the dissociated state in order to integrate the traumatic material held in that state and then reorient the client to the benign present. Like other clients these client also required therapy that addressed their skill deficits in the areas of self, emotion regulation, distress tolerance and dealing with interpersonal conflict.

Our research has some implications for the training of therapists and provision of effective therapy for people with somatoform symptoms. 7of the 8 therapists in our study saw clients for long term therapy. Funding in Australia favours short term therapies. Our study indicates that effective therapy for people with complex psychiatric comorbidity including somatoform symptoms requires long term therapy embedded in a safe therapeutic relationship.

Our therapists received no specific training for the treatments that they were able to effectively deliver. Their expertise was gained in the process of therapy. Confusion, transference and countertransference challenges were regarded as a normal part of the reflective approach they took to enquiry about their client's symptoms. Our participants emphasised the importance of

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appreciating the effect of chronic early attachment trauma on adult mental health across a spectrum of disorders and the need to make painstaking enquiry about that trauma in order to understand its expression as somatoform symptoms.