

THE UNIVERSITY OF HULL

Exploring the experience of psychogenic syncope following diagnosis

Being a Thesis submitted for the Degree of Doctorate in Clinical Psychology

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By

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To the sea, the sky, and paths traversed, leading me on.

Overview

This portfolio has three parts.

- I. **Part one** is a systematic literature review entitled 'What are the psychological factors associated with psychogenic syncope or psychogenic non-epileptic seizures? Psychological factors that appear to be commonly linked to syncopal events of unknown medical origin are explored in relation to psychogenic syncope. Studies have widely acknowledged psychological distress in this patient group. The prevalence of psychological factors and their impact on people remains uncertain. A systematic search of four databases identified eleven studies. The findings are summarised and discussed from various perspectives. Clinical implications and areas of future research are highlighted.
- II. **Part two** is an empirical paper, utilising Interpretative Phenomenological Analysis (IPA) entitled: 'What are the experiences of people diagnosed with psychogenic syncope?' The study explores peoples' perspective of living with psychogenic syncope. A total of six people chose to participate in the study, which employed a semi-structured interview based on the self-regulation model (Leventhal, Nerenz & Steele, 1984). Five superordinate and seven subordinate themes emerged from the data. Peoples' experience of psychogenic syncope was conceptualised by drawing on various theories in order to highlight a need for holistic healthcare practice. Wider psychosocial influences on people diagnosed with psychogenic syncope were also considered.
- III. **Part three** comprises appendices relating to part one and part two. Included in this is an epistemological statement of the stance of the researcher, and a reflective statement on the process of conducting the research, and its challenges.

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Part One

Systematic Literature Review

A systematic review on the factors associated with psychogenic syncope and psychogenic non-epileptic seizures.

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This paper is written in the format ready for submission to '*The International Journal of Cardiology*'. Please see Appendix A for the Guidelines for Contributors.

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Abstract

Background. Psychogenic syncope (PS), psychogenic non-epileptic seizures (PNES) and non-epileptic attack disorder (NEAD) or non-epileptic seizures (NES) are a group of conditions that are medically unexplained that have in common a temporary loss of consciousness. PS, is diagnosed within cardiology syncope clinics. The majority of patients are diagnosed through the epilepsy route in neurology. Studies have widely acknowledged psychological distress, depression, and trauma in this patient group.

Method. This present review aimed to summarise the psychological factors that are reported to be associated with these conditions. To compare their description and evaluate the evidence that associates psychological factors with this group of conditions, which for the purpose of this review are collectively described as PS. A systematic review of four databases (PsycINFO, Medline, CINAHL, Web of Science) was conducted in July 2014, for literature that met the study criteria from 1989-2014. Inclusion and exclusion criteria were applied and a diverse array of 11 studies were identified.

Results. The selected studies were disparate in their findings, interpretation and directions but analysis of the studies identified several factors associated with the conditions: dissociation, anxiety, stress, abuse, trauma, anger, depression, somatisation, and bereavement.

Conclusion. The findings concur with key literature in the field, and highlight factors such as anger, head injury, and bereavement. Considering the extent of PS, under its various terms, literature is limited that draws together psychological factors in a more holistic approach in patient care. There is a need for further research to address this, specifically within the cardiology speciality.

Key words: psychogenic syncope, psychogenic non-epileptic seizure, non-epileptic attack disorder, psychological, systematic literature review

“Every abstract picture of the world is as impossible as a blueprint of a storm... Don't be ashamed because you're human: be proud! Inside you, vaults behind vaults open endlessly. You will never be finished, and that's as it should be” (Tranströmer, 2006, p.191)

1. Introduction

Psychogenic syncope (PS), psychogenic non-epileptic seizure (PNES) and non-epileptic attack disorder (NEAD) belong to the widely acknowledged area of medically unexplained symptoms (MUS). PS provides a consistent challenge for health services for example, the lack of a definitive medical explanation; leading to a gap in efficacious interventions and difficulties of communication of a diagnosis for both the clinician and the patient (Karterud, Knizek, & Nakken, 2009; Reuber, House, Pukrop, Bauer & Elger, 2003). For PS, generally diagnosed via cardiology services, there remains uncertainty in the prevalence and specificity of psychological factors that may be present. Investigation into unexplained syncope (US) presentations occurs throughout the medical specialities of neurology or cardiology. Synthesis of the available evidence and understanding may facilitate improved management and support for patients, and identify interventions.

A definition of PS diagnosed via cardiology is ‘functional’¹, an absence of gross movement, of ‘psychiatric origin’, and characteristic of somatisation (European Society of Cardiology Guidelines, ESC, 2009). Whereas, PNES and NEAD, or non-epileptic seizures (NES) diagnosed within neurology specialisation or epilepsy domains, resemble epileptic seizures with no organic cause (Bodde et al. 2009). The gold standard for diagnosis within neurology specialities is video-EEG² (VEEG) monitoring (Mostacci, Bisulli, Alvis, Baruzzi & Tinuper, 2011). In cardiology, diagnosis is usually made if the patient passes out or convulses on a tilt table test³ without physiological changes occurring for example, a drop in blood pressure

¹ A disease or disorder of physiological function with no known organic basis, termed ‘psychogenic’ in psychiatry

² VEEG records scalp neural activity under observation or monitoring a syncopal event in order to rule out epileptic seizures

³ A tilt table monitors BP and heart rhythm during supine and standing postures to ascertain whether syncope occurs as a result of changes in physiological parameters

(Grubb et al, 1992). It appears that individuals across the medical specialisations with these conditions 'faint' in the absence of a clearly defined physiological reason. More so, the various diagnostic labels appear to be dependent on the medical speciality route to which patients have been referred for example, PS via cardiology or PNES via neurology. However, these varying terms appear to have distinct similarities in presentation and will be termed 'PS' for the purpose of this review (Wessely & White, 2004; Richardson & Engel, 2004; Nimnuan, Hotopf, & Wessely, 2001). Literature reports that psychological factors are associated with PS. In this review, factors may be defined as variables that influence the health of individuals for example, internally perceived such as feelings of stress, emotion, thoughts and beliefs, or external, such as psychosocial. For example, anger or stress may mediate or be a mechanism that contributes to the experience of PS (Reuber, 2009). Equally, psychosocial factors such as relationship conflict may for example, precipitate or perpetuate PS (Brown, Syed, Benbadis, LaFrance, & Reuber, 2011; Reuber, 2009). The factors will be identified from the range of research to date.

Specifically, PS presentation has been described as more frequent than epilepsy, has patient suggestibility, maintained awareness during syncopal episodes, and patients may be unresponsive with closed eyes (Benbadis, 2013). The author explains that this presentation may be related to dissociation and therefore uncontrollable. Literature appears to concur that it may be an involuntary distress signal (Brown et al., 2011; Reuber, 2009).

Hence, PS may be a 'mediator of distress' for example, emotional pain or mental states are experienced in context, translated into 'symptoms' such as fatigue or anxiety, enact through the body, and are categorized as 'somatisation' (Richardson & Engel, 2004). It has been suggested that underlying psychological factors in PS may be attributed to adverse life events, which cluster as symptoms within somatisation (Bodde et al. 2009). In other words, individuals may be unconsciously

influenced by their perception of and their 'lived experience' in their environment (Merleau-Ponty, 1962).

Comorbid factors reported in PS are for example, somatisation⁴, dissociation⁵, PTSD, abuse, avoidance or anxiety (Fritzsche, Baumann, Gotz-Trabert, & Schulze –Bonhage, 2013; Bodde, Kruijs, Ijff, Lazeron, & Vonck, 2013; Bédard, Marchand, Kus, & D'Antono, 2010; Jones et al., 2010; Bodde et al., 2009; Graf et al., 2007; Kouakam et al., 2002). Equally, there may be a coexistence between cardiac syncope and PS, or epilepsy and PNES or NEAD; resulting in a lengthy diagnostic process (Hadjikoutis, O'Callaghan & Smith, 2004). Although frequent reporting of symptoms may occur in MUS (Costa & McCrae, 1987), this may be explained by a lack of social understanding around for example, somatisation or unexplained conditions, so individuals may seek medical diagnoses for clarification (Langfitt, 2007).

How psychological factors are interpreted or diagnosed is dependent upon culture and the era in which we reside. For example, Kleinman (1982) highlights that in China, MUS are more socially accepted than in the West, therefore less psychosocial distress is reported, due to decreased perceived stigma.

Consequently, isolation or social unity in illness, and perception of stigma, may depend on the prevalent social system (Yeung & Kam, 2005; Young, 1989).

Equally, language may be a perpetuating factor in stigmatising 'female illnesses', for example the use of the term 'hysteria' in literature to describe PNES or PS (Alsaadi & Marquez, 2005). In contrast, 'neurasthenia' is known to be a socially "acceptable illness", culturally and historically (Kirmayer, 1984). The reason for the

⁴ Multiple, recurrent changing symptoms, with a long complicated history of service contact, with negative investigations. Symptoms may be referred to any part of the body. The course is chronic and fluctuating, and associated with social, interpersonal disruption (ICD-10)

⁵ Dissociative [conversion] disorder: previously classified as "conversion hysteria" presumed to be psychogenic in origin, associated with traumatic events, insoluble and intolerable problems, or disturbed relationships and evidence that the loss of function is an expression of emotional conflicts or needs. Symptoms may develop in relationship to psychological stress (ICD-10)

high prevalence of females, 75-85%, diagnosed with PS is widely debated (Raj et al., 2014; Alsaadi & Marquez, 2005; van Merode, De Krom, & Knottnerus, 1997), and has been attributed to abuse, anger or helplessness (Reuber, 2009). Anger may be due to unexpressed emotion in females, or social injustice (Arnault & Kim, 2008). In support, a lower prevalence of PNES has been found where expressed anger is more socially accepted for example, in African American culture (Rosenbaum, 2000). Subsequently, evidence indicates that cultural factors, suppression of female roles and emotional expression may be related to the higher prevalence in women (Showalter, 2014; Tasca, Rapetti, Carta, & Fadda, 2012; Reuber, 2009; Scull, 2009).

The biopsychosocial model usefully demonstrates the diversity of factors that may influence individuals with PS (Reuber, 2009). These include predisposing, precipitating and perpetuating factors such as adverse childhood experience, conflict and stress or isolation, respectively. Also, psychosocial factors such as stigma, unemployment, or isolation may negatively affect coping and health beliefs, and importantly recovery (Department of Health, [DoH], 2011; Karelina & DeVries, 2011, respectively). A causal relationship or influence may exist between psychological factors, and PS. However, there are multidirectional influences in PS, as illustrated by the biopsychosocial model (Reuber, 2009). Hence, the specific psychological mechanisms of PS remain uncertain and are insufficient in themselves as an aetiology of PS.

The self-regulation model (SRM) demonstrates that peoples' beliefs or perceptions of their illness may influence their adjustment to illness and coping (Baumann, 2003; Moss-Morris et al., 2002; Leventhal, Nerenz & Steele, 1984). For example, mediating factors such as anxiety or depression may play a role in dysfunctional coping behaviour. Equally, either may increase rumination or hyper-vigilance of health threat, especially in a chronic illness (Baumann, 2003). Importantly, research

widely indicates that anxiety may be prevalent in individuals diagnosed with PS. This may especially be due to the medically unexplainable nature of PS, and the subsequent lack of an illness representation for the patient. It is indicated that individuals diagnosed with PS may experience anxiety and poor adjustment to illness on a daily basis (Hansen, '2014 in preparation').

Psychogenic syncope lies within subjective experience, and therefore is reliant on subsequent interpretation and communication of its symptoms by the clinician and the patient. The medical model, which may consider 'physiological data' more 'real' than subjective experience may contribute to the inherent difficulties in patients and health care providers in understanding the complexity of a psychogenic condition (Helman, 2007, Dijk & Wieling, 2013 respectively). Consequently, identifying the psychological and psychosocial factors that affect individual well-being in PS, may lead to improved clinical assessment, diagnosis and intervention (DoH, 2011; Plesk & Greenhalgh 2001; 2006).

This review aimed to summarise and explore the psychological factors that are reported in a diverse literature base, in order to compare their description and what is known to date. The clinical relevance of identifying factors associated with PS, is that specific interventions can be targeted to support patients and their families, and add to knowledge to improve healthcare within NHS services. Identifying areas for future research and clinical implications are highlighted from the results, and the quality of the reported findings will be evaluated.

Therefore the review question was:

What are the psychological factors associated with PS?

For the purpose of this review, PS has been defined and described as a temporary or partial loss of consciousness, collapsing without a known medical cause. There may be sensations and altered body movements, related to psychological

processes, without the neurological activity that is seen in epilepsy (Reuber & Elgar, 2003).

2. Methodology

2.1. Data Sources

Databases selected for review in July 2014 were CINAHL, PsycINFO, Medline, and Web of Knowledge. These databases were chosen as they reflect available literature across the medical and psychosocial domains. Hand searches were carried out on reference lists from included articles to ensure additional relevant studies were included. Secondary sources included conference papers accessed to obtain references for primary sources. Publication bias was accounted for by scanning grey literature, conference proceedings and unpublished studies. Key authors were contacted in the process of selection. Inclusion and exclusion criteria for the search are shown in Table 1.

Table 1. *Selection Criteria for included and excluded studies*

Inclusion criteria	Rationale
Published in English	To prevent loss in translation
Age 18+	PS less likely in children (Wieling, Ganzeboom & Saul, 2004)
Peer-reviewed journals	To maintain quality
Published 1989-2014	Based on first appearance of literature, and comprehensive synthesis of available literature to date
Quantitative, qualitative or mixed designs	To optimise the scope of the review
Male and female participants	Due to high prevalence of females, information would be valuable on male characteristics in PS
International studies	May indicate different descriptions or symptom patterns dependent on cultural context
Exclusion criteria	Rationale for exclusion
Pharmacological studies	Medication may have an effect on psychological well-being and cause syncope
Lack of a definition of PS	A specific definition to identify a PS diagnosis
Literature reviews	Selection bias in secondary analysis may occur depending on area of expertise (Pannucci & Wilkins, 2010)
Medical reasons for US	To eliminate organic causes of syncope: chronic illnesses; neurological diseases; or major head injury
Mixed sample	Comorbid samples of epilepsy and PS may not show clear psychological characteristics related to PS
<p>Specific studies on: Post-traumatic Stress Disorder (PTSD), sexual abuse, war veterans, family relationships, personality disorder, hysteria, conversion disorder, diagnosis, treatment, management, clinical communication, clinical and neurological features or tests, and epilepsy as the main focus, were outside the scope of this review. Although it is acknowledged that this may provide additional useful insights into the phenomena of PS. The primary aim was to focus on the extent of the commonly reported psychological factors to date with a view to highlighting other reported factors found within the selected studies</p>	

2.2. Search Strategy

A scoping search determined a clear search strategy of search terms that could identify a medically unexplained loss of consciousness, related to PS. The electronic search was performed in July 2014 (see Table 2.). An initial scoping review of key research identified: psychosocial, depression, anxiety, stress, trauma and abuse as psychological factors frequently reported in PS literature. The search terms used were:

Table 2. *Final search criteria for the literature review*

Search criteria	Search terms
All text	<i>“Psychogenic syncope” OR “psychogenic non-epileptic seizures” OR PNES OR “non-epileptic attack disorder*” OR NEAD OR “non-epilepsy attack” OR “nonepileptic attack disorder*” OR “unexplained syncope” OR “functional syncope” OR “apparent syncope” OR “fainting with no medical cause”</i>
All text	<i>AND “psycholog*” OR psychosocial OR biopsychosocial OR depress* OR anxi* OR trauma* OR abuse* OR stress* OR “mental health” OR psychiatric</i>

An initial search strategy found a total of 1352 results, which reduced to 837 after the parameters were applied. After removal of duplicates, 419 titles screened for relevancy left a total of 29. An abstract and a full text assessment, which employed inclusion and exclusion criteria, rejected a further 23 studies. A hand search of the bibliography of included articles identified six additional studies. In total, 11 papers were included. One study was identified via contact with authors but excluded due to being in abstract form only (Noergaard & Becser, unpublished abstract). However, this was included as grey literature to inform the discussion. Article selection is outlined in *Figure 1*.

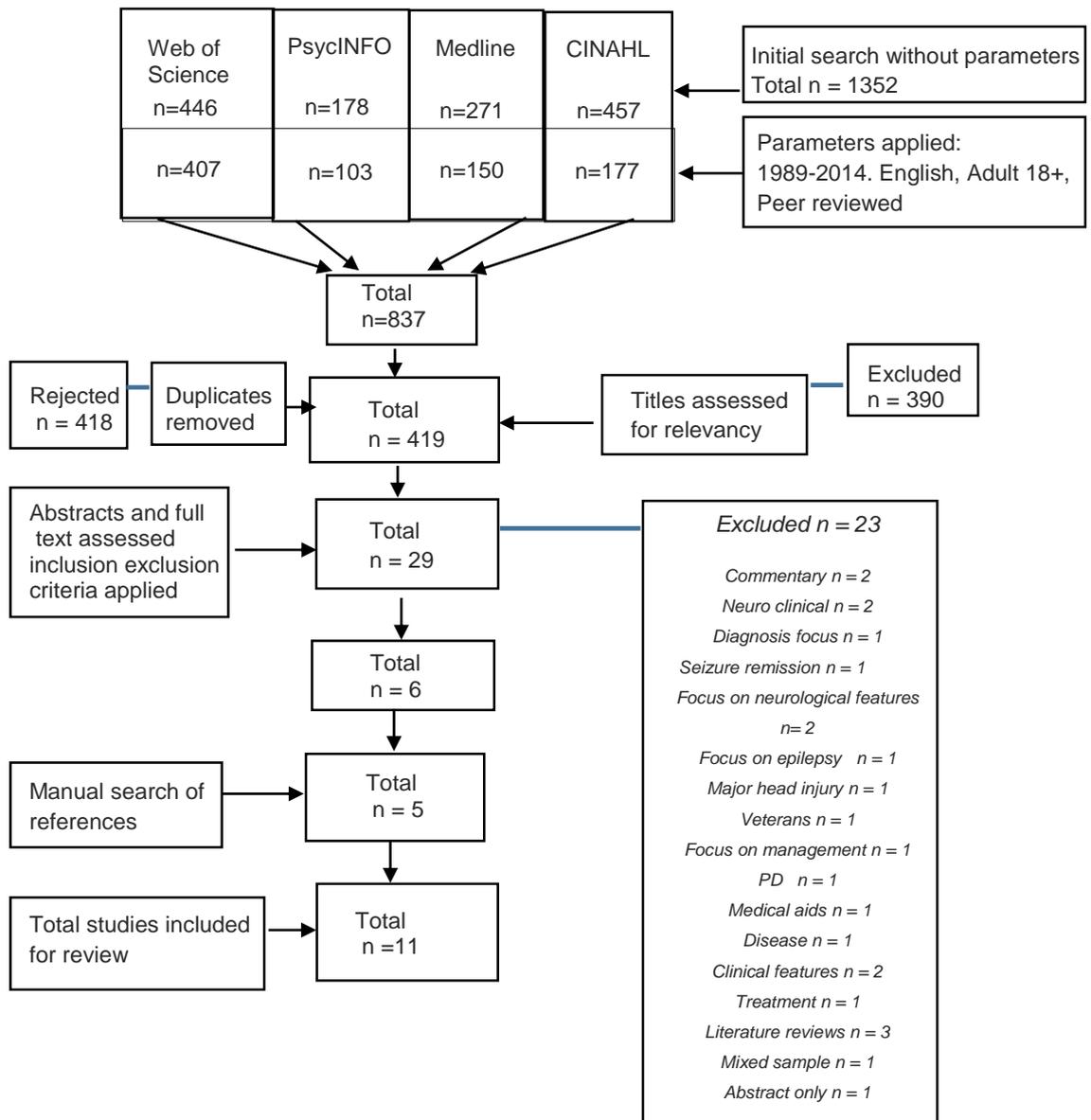


Figure 1. Flow chart to outline the article selection process

2.3 Quality Assessment

An adapted quality assessment tool was employed to allow for the different number of methods and designs used in studies included in the review. The adapted quality measures were from STROBE (Vandenbroucke et al. 2007), which was developed for health care, and has reported high validity for observational studies. The assessment allowed for the specific characteristics of each study to be ascertained and assessed (see Appendix C). The final percentage scores were based on 100% being the highest score quality. For inter-rater reliability assessment, six studies were chosen from a selection of the highest, middle and lowest quality score and blindly rated by an independent researcher who was in full agreement with the quality ratings.

2.4. Data Analysis

Due to the diversity of studies investigated; relating to the different measures and methodologies, a meta-analysis would not have been appropriate. A narrative synthesis of data was employed to identify factors associated with PS within the studies. This method enables the integration of heterogeneous studies; with varied design, measures, and participant characteristics, which is critical to establish key information that may be inherent across the studies (Dixon-Woods, Jones, Young, & Sutton et al., 2005).

2.5. Data Extraction

A data extraction tool to review the selected articles (see Appendix B) recorded: author(s), the aims of the study, design, participant characteristics, measures, the main findings, and the quality score for each study. In addition, the medical speciality from which the patients were identified as experiencing PS was noted.

3. Results

3.1. *Characteristic summary of included studies*

The main findings of the 11 studies are illustrated in Table 3. The mean age in the PS group, across nine of the studies, was 37.44 years, with an age range between 18-65 years, with no reported significant age differences between groups overall. There was an average of 79.5% proportion of females, which indicates that the studies represent the current literature of the population in age and gender (Alssadi & Marquez, 2005). There was an overall total of 508 participants diagnosed with PS in the studies. Results indicated that factors were heterogeneous across the studies, in design and measurements used. Equally, there was a range of international literature found in this review in the included studies. The international representation of studies showed findings from Argentina, Brazil, Norway, Denmark, Italy, U.S, Portugal, U.K, Bosnia, and The Netherlands. However, only one study [10] reported on ethnicity. Interestingly, the majority of studies were all relatively recent apart from Moore & Baker (1997).

The study designs were all quantitative and used various analyses: between-groups analysis of variance (ANOVA) (n = 3), multiple regression (n = 1), logistic regression (n = 1), Chi Square analysis (n = 3), Independent T-test (n = 1), and number of cases (n = 2). Two studies aimed to identify psychological characteristics in a NEAD/PNES group only (Moore & Baker, 1997; Myers, Lancman, Laban-Grant, Matzner & Lancman, 2012). The majority of the studies were case-control and compared PNES to epilepsy (Awad & Softiç, 2011, van Merode, et al. 2014; Proença, Castro, Jorge & Marchetti, 2011; Tojek, Lumley, Barkley, Mahr & Thomas, 2000); whereas three studies compared PS to comorbid epilepsy (D'Alessio et al., 2006; Marchetti, et al., 2008; Mitchell, Ali & Cavanna, 2012). Mökleby et al. (2002) compared PS to somatic disorder and healthy controls, whereas Turner et al. (2011) compared PS with epilepsy, and comorbid epilepsy.

Due to a lack of studies reported via cardiology diagnostic routes, psychological factors were highlighted from within PNES, NEAD and NES and defined as PS.

3.2. Methodological Quality Overview

The majority of studies presented with good rationale, background information, discussion, and sufficiently executed their objective. Most studies gave a definition of concepts investigated and stated sample inclusion criteria although not always exclusion criteria. Methods and results were clearly presented by the majority of studies, although the limitations and generalizability of findings were not considered in some studies. The quality assessment tool for this review indicated varied results in the quality of the studies; from 1 to 20 out of a total of 22 points. Overall, the quality of the studies ranged from 45% to 85% with a mean of 64% (see Appendix D). The studies utilised a variety of assessment measures to identify psychological factors that may be associated with PS (see Table 4.) Overall, in 9 out of 11 studies the measures were of acceptable quality (81%). Only one study (van Merode et al. 2014) performed a double-blind method in assessment and analysis of data to reduce bias in psychiatric diagnosis. Most of the studies demonstrated good validity and reliability of standardised measures, which indicates confidence in the measurement of the reported factors. One study (Moore & Baker, 1997) drew results from retrospective reports only. Additionally, sampling of in-patients from a tertiary ward (Turner et al. 2011) indicates that selection bias may have been inherent in this convenience sample. For example, inpatients may have had more complex conditions preceding admission or the inpatient environment may be more controlled than those in the community. So the findings may not have been representative of the PS population. Notably, causality between the variables studied cannot be determined in the case-control designs.

Overall, socio-demographic variables were considered by six studies, which demonstrates that wider variables, with their influence on PS presentations were not taken into account in half of the studies. Moore & Baker (1997) had the largest sample (n = 185) and findings concurred with literature in prevalent life stressors, anxiety, abuse and bereavement amongst PS patients.

Finally, the majority of studies were from researchers in neurology or psychiatric specialisation, which highlights the deficit in research from a cardiology and psychological perspective. This may be due to mind-body epistemology with brain viewed as disease in medicine (Slavney, 1993; Churchland, 1983).

The implications of the methodology, and a lack of psychosocial consideration in half of the studies are discussed in the next section. Table 3. reports the overview of the studies and their findings.

Table 3. Overview of study findings

Author Date Country	Study No.	Study Aims	Design Characteristics	Participants	Measures	Key findings	Quality Score (QS)	Specialisation Context
Awad and Softic (2011) Bosnia Herze- govina	1	To explore the psychological characteristics of non-epileptic seizures (NES) to epilepsy	Case - control study Chi-square analysis p<0.05	Total n = 80 Epilepsy n =40 NES n = 40 Age: 18+	Psychiatric and Psychological reports (diagnoses) ICD-10 and DSM-IV	Neurotic disorders were found to be lower in the NES group* compared to controls* Dissociative disorders and Stress disorders were higher in the NES group* compared to controls* (*p=0.025) Psychosocial factors defined as vulnerability, social deficits, indifference and insomnia were higher in the NES group compared to controls.	45%	Neurology

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
D'Alessio et al. (2006) Argentina	2	To describe similarities and differences in psychiatric, epidemiological and semilogic factors between three patient groups	Case-control Pearson's Chi-squared test	Total n = 43 PNES n = 24 Females n = 19 (79%) $p < 0.05$ Males n = 5 Mean age = 33.42 ($SD = 14.08$) Comorbid epilepsy n = 19 Females n = 10 Males n = 9 Mean age = 28.53 ($SD = 8.3$)	Psychiatric diagnosis: SCID-I and SCID-II interviews (Spanish versions) DSM-IV	Dissociative disorder was significantly higher at ($p < 0.026$) Conversion disorders were equal between groups. PTSD ($p < 0.045$), Anxiety, and Somatoform disorders were found more frequently in PNES. Psychiatric institutionalization was higher at 33% in PNES ($p < 0.05$)	60%	Epilepsy
Marchetti et al. (2008) Brazil	3	To describe the psychiatric diagnosis of a group of PNES patients	Case-series consecutive	Total n = 28 Female n = 93% Age range 19-62 Mean age = 37 ($SD = 10$) PNES n = 14 PNES and epilepsy n = 13 PNES not confirmed n = 1	'Open clinical' psychiatric interviews DSM-IV	In the PNES group n = 14 psychiatric diagnosis indicated Conversion and Somatization disorders with comorbidities of Depression n = 4 Anxiety n = 1 Dissociation n = 1 Absence of comorbidity: n = 6	45%	Epilepsy and Psychiatry

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
van Merode et al. (2014) The Netherlands	4	To assess psychopathological symptoms and childhood trauma in early psychogenic seizures	Case-control Double blind Two way analysis of variance (ANOVA) for NPS x PS and female x male with age as a covariate p<0.05	Total n = 178 Epilepsy non-psychogenic seizures (NPS) n = 138 Mean age = 49 (SD = 19) Psychogenic seizures (PS) n = 40 Mean age = 35 (SD = 18)	Symptom checklist (SCL-90) Childhood Trauma Questionnaire (CTQ) Self-Rating Anxiety Scale (SAS) State-Trait Anxiety Inventory (STAI) Dissociative Experience Scale (DES) Quality of Life in Epilepsy Inventory (QOLIE-31) Utrecht Coping List (UCL) (Validated Dutch translations)	The PS group scored significantly higher on the SCL, CTQ, DES, SAS, STAI-State and STAI-Trait measures ($p<0.05$). The percentage of females was not significantly higher in the PS group compared to the NPS group (65% and 50% respectively). There was no significant effects of sex, nor effects of interactions. Age indicated a significant covariate with the CTQ with more frequent reporting in older patients ($p<0.05$)	70%	Neurology and Psychiatry

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Mitchell et al. (2012) UK	5	To examine the characteristics and prevalence of dissociative experiences in patients with NEAD and assess the association with health-related quality of life	Cross-sectional Independent T-test Mann-Whitney Fisher's Exact Test Shapiro-Wilk Test	NEAD group n = 39 Female n = 69.2% Mean age = 41.6 (SD = 15.1) Dual diagnosis n = 11 Female n = 72.7% Mean age = 43.4 (SD = 12.4)	Dissociative Experience Scale (DES) Quality of Life in Epilepsy Inventory (QOLIE-31) Beck Depression Inventory-II (BDI-II) State-Trait Anxiety Inventory (STAI) DSM-IV-TR National Hospital Seizure Severity Scale (NHS3)	Dissociation was most frequently reported by the NEAD group, with the Absorption and Imaginative Involvement subscale being the most common experience. The BDI-II indicated lower levels of depression in the NEAD group. There were no significant differences between the groups overall.	85%	Neuropsychiatry

Author Date Country	Study No. Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Mökleby et al. (2002) Norway	To investigate the prevalence of psychiatric comorbidity, anxiety, depression and aggression in patients with PNES compared to patients with somatoform disorder (SD) and healthy controls (HC)	Case-control Analysis of variance (ANOVA) T-tests	Total n = 69 Age range 18-60 years old. Age and sex-matched groups Female n = 19, Male n = 4 in each group PNES group n = 23 Mean age = 32.14 (SD = 9.59) SD group n = 23 Mean age = 32.17 (SD = 7.23) Healthy controls (HC) n = 23 Mean age = 30.04 (SD = 9.21)	Psychiatric history International Diagnostic Interview version 4.4 (MINI) HADS Aggression Questionnaire Scale (AQ)	There were higher levels of psychiatric comorbidity in the PNES group ($p = 0.003$) and higher psychiatric diagnosis ($p = 0.003$). Anxiety, depression and anger were significantly higher compared with HC but not between patient groups. PTSD, Bipolar Disorder and Somatoform Disorder (pain and undifferentiated) were higher in the PNES group. The PNES sample had previous psychiatric hospital admissions for difficulties such as eating disorders, PD, reactive psychosis and suicidal behaviour. Significantly higher hostility was found in the PNES group ($p = 0.019$). Overall, higher numbers of minor head traumas, increased hostility levels, and significant psychiatric comorbidity was found in the PNES sample.	71%	Psychosomatic and Behavioural Medicine

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Moore and Baker (1997) UK	7	To present the psychological characteristics of NEAD	Retrospective study Case record analysis <i>pro forma devised</i> by the authors	Total n = 185 Female n = 74% Mean age 35.6	Case record analysis	Anxiety, stress and 'breakdown' were the highest reported findings at 43%, followed by physical abuse and assault at 28%. Bereavement and relationships problems equally at 26%. Depression was found at 23%. Disrupted childhood at 16%. Sexual abuse/rape at 14%. After this, the most common factors were: pain, suicide, and learning disabilities. The remainder were related to financial, alcohol, eating disorder, and agoraphobia, with PTSD at 0.5%. patients had a psychiatric history; anxiety, depression and suicidal tendencies	48%	Neurology

Author Date Country	Study No.	Study Aims	Design	Participant	Measures	Key findings	Quality Score (QS)	Specialisation Context
Myers et al. (2012) USA	8	To examine factors that contribute to poor quality of life in patients with PNES	Case series analysis, consecutive Multiple regression	PNES Total n = 62 Females n = 87.5% Adult 18+ Mean age = 40.48	Clinical interview QOLIE-31 State-Trait Anger Expression Inventory-2 (STAXI-2) MMPI-2-RF	A significant correlation was found between increased Anger expression (trait) anger-control inwards, and 'cynicism' (RC3) with regard to low QOLIE. The Total Anger score ($p < 0.10$) had a significant association overall with emotional well-being ($p < .004$) and cognitive function ($p < 0.20$). Predictors of low QOL found to be significant were: age of earliest trauma ($p = .006$), trauma history ($p = .017$), STAXI -Trait Anger ($p = .018$)	64%	Epilepsy

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Proença et al. (2011) Brazil	9	To investigate trauma and dissociative phenomena in patients with PNES compared to patients with temporal lobe epilepsy (TLE)	Case-control study Mann-Whitney <i>U</i> Pearson's Chi-Squared test	Total n = 40 PNES group n = 20 TLE group n = 20	Childhood Trauma Questionnaire (CTQ) Dissociative Experiences Scale (DES) (Measures validated in Brazil)	The PNES group had significantly higher DES Total scores ($p < 0.001$) on all subscales, and higher CTQ Total scores ($p = 0.014$) with Emotional Neglect and Emotional Abuse scales significant between groups.	68%	Neuropsychiatry

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Tojek et al. (2000) USA	10	To assess the reported psychosocial factors, stressful life events, and anxiety and depression in PNES compared to epilepsy	Case-control study Chi- Square Regression (adjusted for ethnic groups) Alpha of 0.05 significance	Total n = 58 PNES n = 25 Female n = 88% Mean age = 43.56 (SD = 13.23) African Americans n = 52% (Hispanic n = 1) Epilepsy n = 33 Female n = 90.9% Mean age = 39.60 (SD = 9.03) African Americans n = 30.3%	Life Events Checklist (LEC) Brief Symptom Inventory (BSI) Illness Worry Scale (IWS) Private Body Consciousness Scale (PBS) Toronto Alexithymia Scale-20 (TAS- 20)	The total stress score on all variables was significantly higher among the PNES group ($p = 0.004$). In the PNES group 75% of the specific events in the LEC were more common, significance was found in adult physical abuse at ($p = 0.03$), and bereavement experience ($p = 0.05$). Somatic complaints and higher levels of Body Awareness were more frequently reported in the PNES group	79%	Neurology Psychiatry

Author Date Country	Study No.	Study Aims	Design	Participant Characteristics	Measures	Key findings	Quality Score (QS)	Specialisation Context
Turner et al. (2011) Italy	11	To evaluate psychiatric disorders and neuropsychological functions among patients with PNES, patients with PNES and epilepsy, and patients with epilepsy	Case-control study Analysis of variance ANOVA $p = 0.05$	Total n = 66 Females 64% Age range = 18- 60 PNES n = 22 Mean age = 40.2 (SD = 3.3) PNES and epilepsy n = 10 Mean age = 39.2 (SD = 12.8) Epilepsy n = 21 Mean age = 37.3 (SD = 10.5)	SCID-I and SCID-II interview (Italian version) Neuro- psychological tests	A psychiatric diagnosis was made in 100% of the PNES patients (E 48%). Trauma (psychological trauma, physical abuse, physical illness) was reported at 54% in PNES (E 19%, E+PNES 70%). AXIS 1 diagnosis was at 41% (E 33%, E+PNES 20%). AXIS II diagnosis E 10%, PNES 18%, E+PNES 40%. $p = NS$. Cognitive profiles were not significant between groups.	71%	Neurology

Table 4. Measures employed	Description
Aggression Questionnaire Scale (AQ) (Buss & Perry, 1992)	has 29 items grouped into four factors: physical aggression, verbal aggression, anger and hostility. Anger indicates physiological arousal and represents the emotional component, hostility involves feelings of opposition and injustice and represents the cognitive component (Reyna et al. 2011). The AQ has been validated in different countries, translated into several languages, internal consistency .72 to .80
Beck Depression Inventory-II (BDI-II) (Beck et al., 1996)	a 21-items self-report measure of depressive symptoms; physical and psychological
Brief Symptom Inventory (BSI) (Derogatis, 1992)	Patients rated depression, anxiety, somatic, and psychotic symptoms on a 5-point scale (0-not at all present; 4-extremely). The BSI has high consistency, good internal validity, anxiety, depression, somatization, and psychosis subscales (alpha 0.87, 0.88, 0.83, and 0.69 respectively, (Tojek, 2000).
Childhood Trauma Questionnaire (CTQ) (Bernstein & Fink, 1994)	a 70 item self-report inventory that screens for maltreatment experiences before the age of 18 years. Good internal consistency, test-retest reliability 0.88, (alpha 0.79 - 0.94) (Bernstein et al., 1994; Pavlio & Cramer, 2004).
Dissociative Experience Scale (DES) (Carlson & Putman. 1986)	contains 28 items, participants quantify the frequency of their dissociative symptoms on a scale from 0 to 100%, higher scores indicate more frequent experiences, different factors represented include: amnesia, derealization/depersonalization, absorption and imaginative involvement (items involving absorption in sensory and perceptual experience, commonly used for NEAD patients), good construct validity and reliability is widely acknowledged.
Hospital Anxiety and Depression Scale (HADS) (Zigmond & Smith, 1983).	a self-assessment scale for screening anxiety and depression.
Illness Worry Scale (IWS); (Tojek, 2000)	has 9-items on a 5-point scale to assess concerns about having an illness, (alpha 0.83, Tojek, 2000).
Mini International Diagnostic Interview, Version 4.4 (MINI) (Sheenan et al., 1998)	A short diagnostic interview, developed in America and Europe by psychiatrists and clinicians, for DSM-IV and ICD-10 psychiatric disorders; mood and anxiety disorders, eating disorders, psychotic disorders, and suicidal risk.
Life Events Checklist (LEC) (Kelly et al. 1997)	is a measure for the frequency and severity of 32 significant life stressors, using a 4-point scale for the stressfulness of each event, and the frequency that participants thought about each stressor is rated on a 5- point scale. The mean stress severity score is assessed.
Minnesota Multiphasic Personality Inventory 2-RF (MMPI-2-RF) (Ben-Porath & Tellegen, 2008)	a 338-item self-report measure of psychopathology and personality, - which comprises 338 true-false items. The three scales: somatic complaints; low positive emotions, cynicism were of specific interest given their potential relationship to PNES (Myers et al., 2012).
The National Hospital Seizure Severity Scale (NHS3) (O'Donoghue Duncan & Sander J.W., 1996).	a measure of seizure severity
Private Body Consciousness Scale (PBS) (Miller et al. 1981)	Bodily awareness is assessed on a 5-point scale with this 7-item measure of awareness of bodily sensations, such as temperature and hunger. It has moderate internal consistency (alpha_0.60) and good convergent and divergent validity.
Quality of Life in Epilepsy Inventory (QOLIE-31) (Cramer et al., 1998)	a 31-item measure of health related quality of life.
Structured Clinical Interview for DSM Disorders (SCID-I). (First et al. 2002)	a measure to determine DSM-V Axis I psychiatric diagnoses
Structured Clinical Interview for DSM Disorders (SCID-II) (First et al., 1997)	a measure to determine DSM-V Axis-II personality disorder diagnoses.
Self-Rating Anxiety Scale (SAS) (Zung, 1971)	a 20-item questionnaire.

State-Trait Anger Expression Inventory-2	a 57-item self-report measure, which measures the intensity of angry feelings and the extent to which a person
(STAXI-2) (Spielberger et al., 1983)	feels like expressing anger at a particular time; the Trait Anger Scale measures anger frequency over time, the Anger Expression-Out scale measures how often anger is expressed verbally or physically; the Anger Expression-In measures how often angry feelings are suppressed; the Anger Control-Out measures how often the person controls anger; and the Anger Control-In, which measures how often anger is controlled.
State-Trait Anxiety Inventory (STAI) (Spielberger et al., 1983)	a measure of subjective anxiety.
Symptom checklist (SCL-90) (Arrindel & Ettima, 1986)	a multi-dimensional index of psychopathology
Toronto Alexithymia Scale-20 (TAS-20) (Bagby & Taylor, 1994)	a 5-point scale measure to assess difficulty in identifying feelings, communicating feelings, and externally oriented thinking (alpha-0.71).
Utrecht Coping List (UCL) (Shreurs et al. 1993)	a 47-item questionnaire that measures coping behaviour, active and passive. Good internal consistency.

3.3. Overview of psychological factors

Due to the diverging aims, methods and measures used, the findings relating to psychological factors were varied. Those that emerged were reported to be associated with the experience of PS. Nine psychological factors were associated with PS in the studies as shown in Table 5.

Table 5. Psychological factors and studies that reported on them.

Psychological Factors	Studies that reported on the construct	No. of Studies (Total n = 11)	Reported high frequency or an association	Conditions in which found
Dissociation	Awad et al. ¹ , D'Alessio et al. ² , Marchetti et al. ³ , van Merode et al. ⁴ , Mitchell et al. ⁵ , Proença et al. ⁹ , Turner et al. ¹¹	n = 7	n = 5 ^{1, 2, 4, 5, 9} (71%)	PNES (n = 2) NES (n = 1) NEAD (n = 1) PS (n = 1)*
Depression	Awad et al. ¹ , Marchetti et al. ³ , van Merode et al. ⁴ , Mitchell et al. ⁵ , Mökleby et al. ⁶ , Moore et al. ⁷ , Myers et al. ⁸ , Tojek et al. ¹⁰ , Turner et al. ¹¹	n = 9	n = 3 ^{1, 3, 6} (33%)	PNES (n = 2) NES (n = 1)
Anxiety	Awad et al. ¹ , D'Alessio et al. ² , Marchetti et al. ³ , van Merode et al. ⁴ , Mitchell et al. ⁵ , Mökelby et al. ⁶ , Moore et al. ⁷ , Myers et al. ⁸ , Tojek et al. ¹⁰ , Turner et al. ¹¹	n = 10	n = 4 ^{2, 4, 5, 7} (40%)	NEAD (n = 2) PNES (n = 1) PS (n = 1)*
Stress	Awad et al. ¹ , Moore et al. ⁷ , Tojek et al. ¹⁰	n = 3	n = 2 ^{1, 7} (67%)	NES (n = 1) NEAD (n = 1)
Trauma*	Awad et al. ¹ , D'Alessio et al. ² , Marchetti et al. ³ , van Merode et al. ⁴ , Mökleby et al. ⁶ , Moore et al. ⁷ , Myers et al. ⁸ , Proença et al. ⁹ , Turner et al. ¹¹	n = 9	n = 7 ^{1, 2, 4, 6, 8, 9, 11} (78%)	PNES (n = 5) NES (n = 1) PS (n = 1)*
Abuse*	van Merode et al. ⁴ , Mökleby et al. ⁶ , Moore et al. ⁷ , Myers et al. ⁸ , Proença et al. ⁹ , Tojek et al. ¹⁰ , Turner et al. ¹¹	n = 7	n = 5 ^{6, 8, 9, 10, 11} (71%)	PNES (n = 5)
Bereavement	Moore et al. ⁷ , Tojek et al. ¹⁰ , Turner et al. ¹¹	n = 3	n = 2 ^{7, 10} (67%)	NEAD (n = 1) PNES (n = 1)
Anger	Mökleby et al. ⁶ , Myers et al. ⁸	n = 2	n = 2 ^{6, 8} (100%)	PNES (n = 2)
Somatisation	D'Alessio et al. ² , Marchetti et al. ³	n = 4	n = 2 ^{2, 10} (50%)	PNES (n = 2)

*PS: termed 'psychogenic seizures' in the study, clinically defined the same as NEAD

*Trauma definitions varied within studies: PTSD, childhood trauma (undefined), and life events

*Abuse is specifically examined within these studies whether it has been defined as trauma or not

3.4. *Summary review of results*

The majority of studies used the gold standard VEEG monitoring (Mostacci, et al., 2011), which indicates a clear documented diagnosis of PS. Findings from the two studies which did not employ video-EEG (Awad & Softiç, 2011; Moore & Baker, 1997) due to the study design, may not determine whether the results were influenced by comorbid epilepsy or other variables in the diagnosis. The results may have been subject to interpretation bias especially in Moore & Baker (1997), where authors devised a pro forma for analysis (Lijmer et al. 1999). Only one study (Myers et al. 2012) utilised multiple regression to account for possible confounding variables.

The most commonly employed measures were the 'Childhood Trauma Questionnaire' (CTQ)⁶ (Bernstein & Fink, 1994) in two studies, the 'Dissociative Experiences Scale' (DES)⁷ (Carlson & Putman. 1986) in three studies, and the 'State Trait Anxiety Index' (STAI)⁸ (Spielberger et al., 1983) in two studies. In line with literature, trauma, dissociation and anxiety in relation to these measures, were found to be highly associated with the PS group comparatively across the studies. Specifically, Mitchell et al. (2012) found a high prevalence of dissociative experience in association with a poor health-related quality of life (HRQoL, Vickery et al. 1993). This was specifically related to 'low energy/fatigue' and 'seizure worry', compared to people with epilepsy. This may be explained by peoples reported anxiety in PS, and the lack of a clear explanation for their experience of PS (Bodde et al. 2013).

Tojek et al. (2000) found wider implications in ongoing negative life events as a major contributor to a PS, such as interpersonal conflict. This is suggestive of the

⁶ Childhood Trauma Questionnaire a 70 item self-report inventory that screens for maltreatment experiences before the age of 18 years

⁷ Dissociative Experience Scale participants quantify the frequency of their dissociative symptoms on a scale from 0 to 100%, higher scores indicate more frequent experience

⁸ State Trait Anxiety Index: A measure of subjective anxiety

presence of adverse psychosocial factors in PS reported in literature. Interviews for psychiatric diagnoses were conducted in eight studies using various measures. The primarily neuro-psychiatric basis of the studies may suggest observer bias relating to expectations in diagnoses (Caplan, Cosgrove and McHugh, 2004). Additionally, this may highlight a cultural overrepresentation of the medical model within the literature. However, Marchetti et al. (2008) utilised three interviewers and a separate review of results following diagnoses to reduce bias; and van Merode et al. (2014) utilised the double-blind methodology in diagnoses, so the factors identified within these studies may offer more credence. Three studies (van Merode et al. 2014; Myers et al. 2012; Marchetti et al. 2008) reported lower quality of life as a health outcome for people with PS compared to epilepsy, which concurs with literature (Reuber, 2009, Bodde, et al. 2009).

Overall, the factors that studies most commonly examined were depression followed by anxiety and trauma. Of these, it was trauma that was found to be frequently associated with PS in the majority of studies. Potentially, results may have been subject to recall bias using the CTQ (MacDonald, Thomas, MacDonald, & Sciolla, 2014). However, the definition of trauma was not consistent across studies for example, in some studies abuse was defined separately from trauma. The factors least examined were anger, stress and bereavement. Markedly, anger was found to be highly associated with PS in the studies that examined it (Myers et al. 2012; Mökleby et al. 2002). The psychological factors in the studies that were found to be associated with PS were as follows:

Dissociation

Dissociation may be described as a change in memory, consciousness or environmental perception, a discontinuity of the self that may relieve a painful experience (Bodde et al. 2009). Seven studies reported on dissociative experiences and an association with PS was found in five studies. A higher frequency of dissociative experience was reported in three studies (van Merode et al. 2014; Awad & Softiç, 2011; D'Alesso et al. 2006). More specifically, Marchetti et al. (2008) reported that the frequency of symptom reporting correlated with poorer quality of life, and that dissociation was specifically related to the absorption and imaginative involvement scales of the DES (see Table 4). Briefly, it alludes to ability to become fully engaged in perception of an object or 'daydream', a heightened sense of reality (Tellegen & Atkinson, 1974). In contrast, Proença et al. (2011) found significance ($p = 0.001$) on all five subscales of the DES in people diagnosed with PS.

Depression

A number of studies highlighted the widespread reporting in literature of depression in PS. Relevantly, the studies did not find depression to be strongly associated with PS. However, Marchetti et al. (2008) found that depression was a factor that contributed to poorer quality of life. Other studies found that individuals with PNES reported depression more frequently than individuals with epilepsy. However, according to Turner et al. (2011) one reason for the reported association of depression may be that it is more recognisable and therefore easier to diagnose than for example, dissociation. Two studies who investigated psychosocial issues more in depth attributed depression to specific negative life events, such as conflict or relationships (Tojek et al. 2000; Moore & Baker, 1997). In contrast, D'Alessio et al. (2006) found that depression was less reported in the PS group comparatively between groups.

Anxiety

Overall, studies found that anxiety was a frequently reported symptom in the PS group. More specifically, one study found increased levels of trait anxiety associated with PS. This appears to suggest that anxiety may be a chronic characteristic in individuals diagnosed with PS. However, it may be bi-directionally related to the actual experience of PS for people, and various multidirectional influences (Reuber, 2009). In contrast, there was less observed anxiety-disorders and only marginal differences between groups in anxiety levels in two studies (Turner et al. 2011; Tojek et al. 2000). Further to this, psychosocial factors and adverse life events were found to account for anxiety in people with PS (Tojek et al. 2000). On the other hand, a range of symptoms such as fear, dizziness and panic were attributed to 'anxiety expression' (Moore & Baker, 1997). Two studies reported a high frequency of stress or disorders due to anxiety-related stress (Awad & Softiç, 2011, Moore & Baker, 1997). Tojek et al. (2000) attributed PS as a manifestation of stress in relation to somatic disorders, as suggested in literature.

Trauma

Trauma, commonly investigated in PS; includes sexual, physical, emotional abuse, PTSD, or significant life events such as bereavement. Three studies found associations with PS related to childhood trauma (van Merode et al. 2014; Myers et al. 2012; Proença et al. 2011). Emotional neglect and emotional abuse were specifically related to the PS group with higher scores on all the CTQ subscales comparatively (Proença et al. 2011). In contrast, two studies (Tojek et al. 2000; Turner et al. 2011) found that it was physical abuse as an adult that was frequently reported. Equally, a number of traumatic experiences that include physical abuse and assault, sexual abuse, and bereavement, was highlighted by van Merode et al. (2014) and Moore & Baker, (1997). This may indicate a continuum of adverse life experiences in this patient population. Interestingly, the range of publication dates

between these two studies suggests further research into understanding trauma within this patient group is needed. Overall, physical and sexual abuse were the most commonly reported types of abuse in the majority of studies.

Two studies which did not define PTSD in detail reported a frequent association of PTSD with PS. In contrast, one study did not find an association between PTSD and PS (Marchetti et al. 2008). This may possibly be due to nondisclosure in psychiatric interview as opposed to employing a measurement scale for trauma. A number of studies highlighted the widely held association between dissociation and trauma. One study found that minor head traumas were more commonly reported by people with PS (Mökleby et al. 2002).

Bereavement

Bereavement was not well investigated but found to be a commonly reported factor associated with PS (Moore & Baker, 1997; Tojek et al. 2000). Bereavement was defined within adverse life events and described separately from trauma experience in these studies.

Anger

Two studies examined levels of anger in people diagnosed with PS. A novel finding was an association between elevated anger expression and cynicism, with poor quality of life (Myers et al. 2012). The authors' highlighted diminished anger-control inwards specifically as associated with PS. One reason for this may be that anger suppression may be a mechanism of the somatisation process (Liu, Cohen, Schultz, & Waldinger, 2011). Another finding indicated that anger and hostility levels were remarkably higher in the PS group, which the authors suggested may be a coping style in respect to psychosocial factors such as being misunderstood (Mökleby et al. 2002).

Somatic disorders

Somatisation has been described as a mechanism whereby emotions are expressed as external physiological reactions, in order to avoid experiencing emotion distress (Bodde, et al. 2013). Four out of five studies which described somatisation, reported on more frequent associations of somatic disorders in individuals with PS. Specifically, D'Alessio et al. (2006) defined somatic symptoms as 'pain, autonomic symptoms, headache, and dizziness'. Equally, Mökleby et al. (2002) found a high prevalence of pain symptoms, and linked PS as a syndrome within somatisation.

Psychosocial variables

There were few studies that took into account the variables of psychosocial and demographic factors as an influence on individuals diagnosed with PS. Nevertheless, the studies that measured its prevalence, highlighted life specific events and subsequent life stressors that may be precipitators for PS presentations. Specifically, Tojek et al. (2000) found associations in PS with interpersonal relationships, marital difficulties and ongoing relationship problems. Equally, marital and interpersonal difficulties and low levels of unemployment appeared to be prevalent (Moore & Baker, 1997). During interview assessment, social withdrawal and loneliness were most commonly reported (Myers et al. 2012). However, the authors did not find an association with demographic variables and PS. Conversely, a high percentage of individuals experiencing social deprivation was found in Turner et al. (2011). Other psychosocial characteristics within PS were reported as 'social ability deficits' and 'vulnerable character', although these terms were not defined (Awad & Softiç, 2011). In contrast, one study found no difference between groups in socio-demographic variables (Myers et al. 2012). It may be that psychosocial factors represent a continuum of life events that individuals may or may not experience as stressful to traumatic. To explain this, the

individual's response to stress may be dependent on for example, resilience, available social support, or functional coping skills (Reuber, 2009). Hence, the association overall between trauma and people diagnosed with PS is likely to be indeterminable.

In view of the high prevalence of females diagnosed with PS as reported in literature, nine studies supported this. In contrast, van Merode et al. (2014) found less than the average rate, with 65%. One reason for this difference may be that this was a prospective study with incident cases in the general population, which may have reduced the possible selection bias widely found in prevalence based studies. One study did not report on gender.

4. Discussion

4.1. Overview of findings

The principal findings of this review are that there are multifactorial psychological factors associated with PS. Importantly, no literature was found regarding factors associated with PS via cardiology to date. The studies included in this review investigated the factors associated with PS, and other variables such as psychosocial factors. Valuable clinical implications may be drawn from these findings as well as areas for further research. The cultural diversity of the included studies was interesting; all of the studies were from within the Western hemisphere. This may be indicative of the mind-body approach to medicine in the West and its apparent separation of symptoms in the body, compared to the holistic approach in Chinese or Asian culture (Chan, Sze, Cheung, Lam & Shi, 2009; Kleinman, 1982). However, the heterogeneity of the studies may suggest that it is not possible to draw firm conclusions.

The factors that were investigated most frequently in this review were: anxiety, trauma, abuse, depression and dissociation. However, of these, dissociation, trauma, and abuse, were found to be most frequently associated with PS. The

factors least represented were bereavement and anger. An association of anger with PS was found and a novel association of head injury (Mökleby et al. 2002).

The elevated levels of dissociation, trauma and physical and sexual abuse in individuals with PS adds to findings in current literature. A study from grey literature found in this review concurs that trauma as childhood sexual and physical abuse is prevalent in PS compared to the general population (Noergaard & Becser, 2014).

The findings of anger and head injury associated with PS suggest that further research is necessary to examine their prevalence as a means to provide appropriate interventions. The need to identify interventions in healthcare for this patient group appears to be critical considering that PS is frequently associated with trauma, abuse and dissociative experience, with possible consequential anxiety.

In this review psychosocial factors that were associated with PS were highlighted. These included for example, family conflict, unemployment, alcohol or drug problems, a family member with a history of seizures, or bereavement (Tojek et al. 2000, Moore & Baker, 1997). This indicates that psychosocial factors may play an important role for example, in the maintenance or the chronicity of PS, as found in epilepsy populations (Reuber, 2009, Chaplin, Shorvon, Floyd, & Lasso 1995, respectively). Additionally, in chronic pain, psychosocial stressors may reduce adjusting to illness (Valente, Ribiero & Jensen, 2009). Hence in accordance with current health strategies [DoH, 2011), it appears vital to incorporate psychosocial interventions into healthcare for people diagnosed with PS. Further research is needed to investigate psychosocial factors within this population.

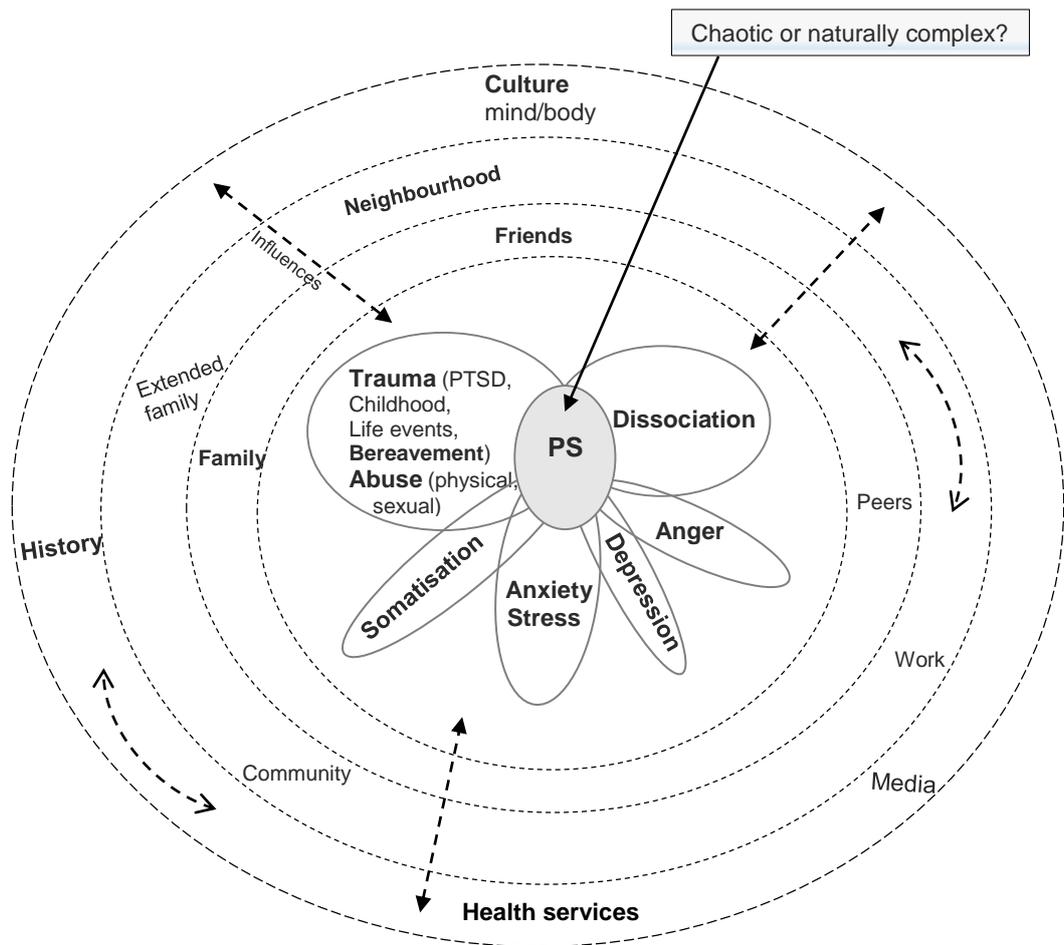


Figure 2. Illustration of the complexity of factors associated with PS (adapted from Bronfenbrenner, 1979, Marchetti et al. 2008, and incorporating Plesk & Greenhalgh, 2001).

The nine factors associated with PS identified in this review are illustrated in *Figure 2*. The heterogeneity of factors found to be present in PS in this review links within the integrative approach to draw understanding of psychosocial factors into healthcare practice (Plesk & Greenhalgh, 2001). The mapping illustrates the possible interrelationships of micro and macro multidirectional influences on the individual who experiences PS, in the context of their social world (Bronfenbrenner, 1979).

To explain this, currently PS may be viewed or 'felt' to be a 'chaotic' presentation, by the patient and healthcare workers (Langton, 1989). A chaotic view of illness is

arguably in opposition to 'simple' conditions, which may facilitate quicker medical explanations (Langton, 1989). In order to create a balance between simple and chaotic, 'complexity' may be a more holistic viewpoint in which to understand the heterogeneous nature of PS. In support, individual experience of PS does not appear to correspond to simple symptom categorization as discrete (Jutel, 2010; Kirmayer, Groleau, Looper, & Dao, 2004). More so, the 'factors' represent experiences that play out in individual lives, individuals are unique and 'lived experience' is naturally complex. For example, multidirectional influences involved with PS may not be identified from one source. Anger or anxiety, as found in this review, may be precipitated or perpetuated by a diagnosis of PS (Reuber, 2009). Equally, the interplay of psychosocial factors may contribute to a PS presentation by elevated levels of anxiety, depression or anger (Reuber, 2009). Overall, in this review depression was not found to be highly associated with PS. Literature that investigated depression found that it was lower in the PS group, compared to people in the epilepsy group. This may be due to the reported elevated levels of depression in people with epilepsy (Kanner, & Balabanov, 2002). The issue of trauma, abuse, or bereavement may link into somatic expression or bi-directionally contribute to stress or anxiety, concurrent with literature (Bodde, et al. 2009; Ricardson & Engel, 2004). Notably, mediating emotions nested in a complexity of possible interactions in PS are unlikely to be singular, other factors if investigated may also become apparent.

Conclusively, there appears to be a lack of an explanatory model in which to represent PS in order to guide health care for this patient group. Multifactorial associations in PS appear to be inherent in the complex nature of this condition. Therefore, a holistic biopsychosocial approach may be clinically relevant for this patient group by providing a framework in which to understand PS and from which to draw interventions (Reuber, 2009; Walker, Jackson & Littlejohn, 2004). This

review has extended the mapping of MUS nosology (Marchetti et al. 2008), in order to illustrate the wider influences such as demographic and psychosocial identified in the literature that may contribute to complexity of PS. Also, as previously alluded to in Western mind-body philosophy, there are cultural and historical influences on individuals and society, as well as the role of the medical model and diagnostic terminology, such as hysteria.

Markedly this review indicates that dissociation appears to be prevalently associated with the experience of PS, which concurs with literature (Baslet, 2011, Spitzer, Barnow, Freyberger, & Grabe, 2006; Fizman, Alves-Lyon, Nunes, D'Andrea, & Fiueira, 2004; Harden, 1997). What is more, a dissociative experience for the patient with PS, may be an overarching one. Qualitative research is needed to explore the impact on the patient of their experience of PS (Hansen, 2014 'in preparation'). Subsequently, the author suggests 'dissociative syncope' as a new diagnostic term, in cardiology, possibly instead of the other current numerous terms relating to a non-epileptic event. It may be that the term 'dissociative syncope' will become less associated with epilepsy. In turn, this may possibly reduce the ongoing attribution of the 'illness' of PS with the brain, which could reduce the sense of a fragmented self as found in chronic conditions (Wisdom, Bruce, Saedi, Weis & Green, 2008; Ware, 1992). Importantly, legitimising the condition for the patient diagnosed with PS in this way, is likely to reduce stigma in the long-term (Stone, 2013; Ware, 1992).

Arguably, the nine factors identified in the included studies highlights a possible lack of a 'person-centred' approach. An illustration to represent the gap between personal experience of PS as opposed to factors or symptoms illustrated in *Figure 3*.

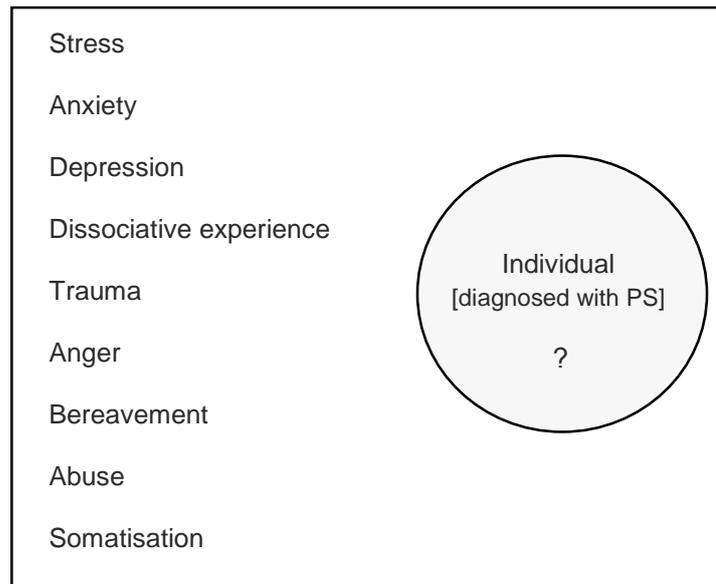


Figure 3. An illustration of ‘factors verses the individual person’

Hence, the lack of qualitative literature in this area identifies the need to investigate the actual meaning of these factors to people who experience them.

Importantly, a key finding is that this review identified the sparsity of literature that investigates PS via the cardiology route. Several points may be raised from this finding. Firstly, the people who go through the cardiology pathway appear to be overlooked to a greater extent than those who go via neurology pathways. One reason for this may be the lack of research and information for clinical direction or intervention to support this group of people. Equally, there appears to be fewer cardiology blackout clinics nationwide. Hence, most literature to date remains within the domain of neurology. It may be ascertained that people who refer through the cardiology route may experience similar psychological symptoms to the people who are treated via neurology. Indeed, there was apparent consistency across the studies in highlighting commonly associated factors within PNES, NEAD, and NES diagnosis. Another reason for a lack of research in cardiology to date may be the relationship of PS to epilepsy and the need to rule out neurological disorders. Alternatively, medical attention may be to prioritise understanding or treating the brain due to the mind-body epistemology. A result of this may be that emotions

have been least explored, hence understanding emotions within PS may prove beneficial in promoting an integrated holistic approach to individual healthcare.

5. Conclusions

The clinical relevance of this study is that individuals may have similar healthcare needs across the PS diagnoses spectrum. Clearly, there is a need for research within cardiology specialisation in order to ascertain the possible homogeneity of their needs compared with patients from neurology specialisations. This review has identified key factors that play a role in PS. Evidenced in this review, in line with literature, is that dissociative experience, trauma, abuse, and anxiety appear to be prevalent factors in PS. Also, it was indicated that less investigated factors in literature such as anger, bereavement and psychosocial factors may play a key role in patient experience. Clearly, the impact of PS as an experience for the patient, coping and adjustment to illness need further investigation in order to move towards a better understanding and a more holistic healthcare approach.

6. Methodology, Strengths, and Limitations

Overall, this review found the included studies to be of good methodological quality. The review identified its aims by exploring the psychological factors found in the studies, and reporting on their prevalence. This is the first review to synthesise psychological factors across diagnostic PS routes. A further strength is that the review employed a systematic methodology, and the application of a specified search strategy, and inclusion and exclusion criteria. This ensured that the research questions were answered as comprehensively as possible, and help to reduce researcher bias. The quality of the studies were considered with an adapted assessment tool that drew on the sections of the studies in an attempt to comparatively evaluate the design and methodological quality. Inter-rater reliability of the assessment was conducted and quality agreed in validation of the findings.

Standardised and validated measures were employed across some studies indicating reliability in the outcomes. Other variables such as psychosocial factors were taken into account, which were indicated to have an association with PS. Sampling mainly consisted of a control group of epilepsy patients, which are considered appropriate comparison groups for PS (Lewallen & Courtright, 1998). Two studies used regression to account for potential confounding variables in the samples such as age, gender, and demographics (Myers et al., 2012; Tojek et al. 2000). Whilst, Mökleby et al. (2002) used matched controls to reduce variables between groups. In order to reduce the effect of sample selection and interviewer bias, a double-blind investigation was performed in the study by van Merode et al. (2014). The gold standard of video-EEG recording was used as a diagnostic procedure for PS in the majority of studies in this review, indicating a definitive diagnosis across the patient groups (Mostacci et al., 2011).

The prevalent factors identified in this review accord with the ongoing weight of literature in relation to dissociative experience, trauma and abuse. Novel findings were highlighted, such as that of bereavement, anger, and head injury. In this review, clinical implications were identified from the literature, which particularly highlight that patient needs in cardiology specialisation require further research.

Importantly, in the majority of studies psychosocial characteristics were overlooked as possible factors associated with PS. This is highly relevant, as psychosocial factors are indicated to be influential in health outcomes across patients with epilepsy (Koponen, et al., 2007). The weakness of the methodology across studies includes small sample sizes, or studies without a control group. Relevantly, patient outcomes such as quality of life were not well investigated in the majority of the studies. So, patient outcomes cannot be established in this review. It was not possible to test for publication bias due to peer review and limited literature relevant

to the research question. Although one unpublished abstract was found to be in agreement with findings in this review.

Temporal biases, inherent in case studies, may have impacted on the results. For example, depression may impact differently on patients and at different stages of assessment (Song & Chung, 2010). Investigations using a longitudinal design may have found different results.

Equally, there may be bias within the findings of this review due to the use of the specific search terms in order to focus the search. However, the terms '*psychological*' and '*mental health*' were employed to search for possible wider factors in the literature. Hence, caution in this review needs to be taken as firm conclusions cannot be drawn regarding the range and strength of factors found to be associated with PS.

Based on the mostly neurological and psychiatric base of the research, a positivist interpretation of analysis may be present in the studies. The absence of qualitative studies in the findings suggest that meaningful analyses of peoples' understanding and viewpoint of PS remains unexplored.

Overall, the findings of this review appear to be reliable and represent this patient group in the general population. Equally, the findings concur with current literature, and suggest a complex profile for PS. The appearance of these factors in this review helps to support growing evidence for their association with PS.

7. Clinical implications

This review indicates that patient experience of PS appears to be adverse with a possible continuum of both personal and psychosocial factors to manage. As suggested by Marsh, Benbadis and Fernandez (2008), and Wakefield (2007) an effective diagnosis may be part of an intervention. This is clinically relevant considering the multiple referral routes for a diagnosis for people with PS.

One way to attain information of prevalent symptoms and improve patient assessment experience, may be to offer a standardized measurement tool in neurology and cardiology assessment. This may facilitate a speedy diagnosis and intervention, to date a standardized assessment does not exist. The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) and/or the Revised Illness Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002) could be utilised as an initial assessment measure across all PS presentations.

The prominence of dissociation, trauma and abuse requires further investigation, and sensitive interviewing skills may be required. Hence, interventions such as 'Compassion-Focussed Therapy' may be useful for abuse, trauma or bereavement in this patient group (Gilbert, 2009). Equally, considering possible chronicity in PS and that patients may 'disappear' from services following diagnosis, early intervention may be crucial (Karterud et al. 2009). Also, healthcare providers may target the patients' understanding of PS in order to increase acceptance of the diagnosis and interventions for better health outcomes.

Further implications of this review may be that clinicians may need to take into account the less well investigated factors, such as bereavement and anger. Anger as a mediator for PS may be of clinical relevance, and deserves further investigation. Anger management, bereavement counselling, or strengthening coping skills by facilitating acceptance of feelings using emotion-focused therapy may help to achieve a better health outcome in PS (Greenberg, 2004). Equally, awareness of the context of the person may help to reduce psychosocial issues, and peer support could reduce any isolation and improve health outcomes (Repper & Carte, 2010)

As literature is limited in cardiology specialisation for PS, conclusions cannot be drawn in this field. However, it may be that PS overlaps, parallel to the similarities

reported across PNES, NEAD or NES, diagnosed within neurology. Further research is required to investigate a possible overlap, and ascertain whether patient groups may be diagnosed under one term. In order to provide interventions research needs to ascertain whether the needs of patients who refer through cardiology may be overlooked, compared to neurology, as suggested by the sparsity of literature in this review.

8. Future directions

The literature to date appears to be limited to quantitative research. Future research may be required to employ qualitative studies to initiate a more holistic understanding of PS, by seeking to understand peoples' experiences, and their family, of PS. This information could make interventions more effective. Research in precipitating and perpetuating factors involved in the individual experience of PS may be useful in order to inform a biopsychosocial based intervention. This could be psychoeducation in schools and communities, which is a developing research area for promoting mental and emotional health, including adjustment to illness, (Lukens & McFarlane, 2004). It was outside the scope of this review to examine the impact on the caregivers of people with PS. However, current research by Yusuf, Nuhu & Olisah, (2013) in epilepsy domains indicates high distress levels in caregivers, the relevance of this is that, considering the psychosocial factors found in this review, family or friends may impact on the recovery process of the patient with PS.

Also, longitudinal designs are needed to ascertain for example, whether factors associated with PS may occur at earlier or later stages of diagnosis. Equally, research into the impact of factors on health outcomes in the long-term may be useful.

Research into the commonly linked factors such as trauma and dissociative experience and their possible interrelationship may be useful. This may determine

whether a more holistic terminology in diagnosis, as opposed to multiple terms, is feasible.

Equally, gender related research is required to examine the needs and experiences of male patients with PS. It may be especially necessary to determine the prevalence and needs of people within minority populations, as this remains unclear to date.

Importantly, research in PS needs to be extended to PS via the cardiology population. This is in order to examine similarities or differences in these patient groups so that interventions may be specifically targeted. Equally, no qualitative literature was found in this review that investigated PS from the patients' perspective via cardiology and remains limited in neurology research.

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Part Two

Empirical Paper

An empirical paper on the experiences of people diagnosed with psychogenic
syncope

What are the experiences of people diagnosed with psychogenic syncope?

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Key words (not in title): holistic, psychosocial, phenomenology

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Abstract

Background: Psychogenic syncope (PS) falls within the term of medically unexplained symptoms (MUS). PS diagnosed via cardiology is not well investigated compared to non-epileptic attack disorder (NEAD) or psychogenic non-epileptic seizures (PNES), diagnosed via neurology speciality. PS may be diagnosed within cardiology clinics via a process of exclusion of cardiac cause. No research to date has explored the experiences of patients who receive their diagnosis of PS via cardiac services. Understanding patient experiences may help provide better management of identified needs.

Methods: The study utilised six semi-structured interviews, from people previously diagnosed with or having a probable psychogenic syncope diagnosis, received via a cardiology service pathway. Interviews were guided by the self-regulation model (SRM) (Leventhal, Nerenz & Steele, 1984). Results were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Five super-ordinate and seven subordinate themes emerged from the data. Descriptions highlighted peoples' sense of disconnection between the mind and body. An emphasis on 'not understanding' PS evolved into an overarching sense of uncertainty, and possible dissociative experience in 'collapsing'. A 'battlefield' was described in relation to fighting the experience of PS. Finally, a loss of identity emerged through feeling different from others. A framework for understanding peoples' experience of PS adapts the SRM and identifies wider psychosocial perspectives. The 'complex adaptive systems' approach (Plesk et al. 2001) is highlighted as a perspective in which to understand PS further.

Conclusion. A holistic approach in which to understand the experience of PS may be useful for the patient and clinician. Research is needed to gain further insight to establish interventions. **Key words:** Psychogenic syncope, Patients' experience, Psychological, Psychosocial, Cardiology

“Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system”. (Merleau-Ponty, 1962, p. 235)

1. Introduction

The cost of medically unexplained symptoms (MUS) for the health service is reported to be in excess of £3 billion, and with patients given repeated referrals and investigations, diagnosis becomes lengthy and treatment can be delayed (Department of Health, [DoH], 2011; Reid, Wessely, Crayford, & Hotopf, 2002). It is widely acknowledged that psychogenic syncope (PS), a medically unexplained condition, lies within a syncopal presentation cluster* with symptom overlap for example, apparent; functional; psychogenic pseudosyncope; dissociative seizures; non-cardiac; non-epileptic seizures; pseudo-seizures, psychogenic non-epileptic seizures (PNES), and non-epileptic attack disorder (NEAD). The more widely recognised NEAD, according to the National Institute for Health and Clinical Excellence (NIHCE, 2010) costs the NHS £24 million a year, or reportedly around £17,000 per patient per year (Magee, Burke, Delanty, Pender, & Fortune, 2014). * (see Appendix N)

Within cardiology, PS is classed as a non-traumatic loss of consciousness, and diagnosed as ‘psychogenic’ without a drop in blood pressure, although loss of postural tone, rapid onset, and complete recovery occurs similar to cardiac related syncope (European Society of Cardiology Guidelines, [ESC], 2009). Professionals within cardiac settings tend to refer to the ESC (2009), which describes PS as a somatic condition. Apart from patient history, the classification of diagnosis can be dependent on whether people are referred through neurology, cardiology or psychiatry, and possible re-referrals across departments. It is indicated that neurology may be the initial referral route for patients due to a transient loss of consciousness (T-LOC) being generally attributed to epilepsy, although reflex syncope appears to be the most common

cause of T-LOC (Fitzpatrick & Cooper, 2006). Equally, the necessary reliance on self-report from the patient or their family may contribute to any uncertainty in diagnosis and the referral route taken (Petkar, Jackson & Fitzpatrick, 2005). The terminology used in cardiology appears to have fluctuated from 'apparent', 'psychogenic', and 'functional', but for the purposes of this study, 'psychogenic' has been used. Furthermore, confusion around PS diagnostic labels appears widespread for patients, families and clinicians (Fitzpatrick & Cooper, 2006).

The pathway for patients referred to cardiology is usually via their GP following reports of collapse or dizziness, or direct referral, after an ambulance to A&E, following a collapse or suspected T-LOC (Petkar, Jackson & Fitzpatrick, 2005). Relevant to defining PS, compared for example to NEAD or other seizures, which mimic epilepsy, is that less gross body movement occurs and the event is similar to that of transient loss of consciousness (Dhiman, et al., 2013; Jones et al., 2010; ESC, 2009). Patients who present at cardiology clinics will undergo numerous tests to eliminate heart disease as a cause of syncope. Tests used to diagnose cause of syncope via cardiology clinics, include detailed history taking, an initial verbal assessment⁹, blood pressure¹⁰, blood tests; and monitoring ECG¹¹. If diagnosis remains unclear a tilt table test¹² will identify any blood pressure and heart rate problems during a syncopal episode. Further assessment may include an implantable loop recorder¹³, used to identify arrhythmias. In cardiovascular syncope, the most common syncopal events are related to cerebral vascular events 21%; cardiac disease 9.5%, which has a high mortality rate; and orthostatic 9.4% (postural hypotension) (Brignole 2007). Substance or alcohol abuse, heat exhaustion, and dehydration are also known

⁹ Patients are asked about their general health and experience of syncope using a questionnaire designed for purpose by the clinicians

¹⁰ BP is taken to determine if patients have a low BP reading which can account for syncope

¹¹ The rhythm and electrical activity of the heart is recorded using a small external digital device

¹² A tilt table monitors BP and heart rhythm during supine and standing postures to ascertain whether syncope occurs as a result of changes in physiological parameters

¹³ A small device inserted under the skin to diagnose abnormal heart rhythms

causes of syncope. Once the tests rule out heart disease or other causes such as dehydration, a 'psychogenic' diagnosis may be made and a referral to psychological therapy offered (ESC, 2009). Equally, patients may be given a follow up appointment, and contact details in case of continuing syncope and concerns. Medically-related syncope is evidential and usually distinctive to diagnose. Conversely, for PS, guidelines are sparse, unlike other MUS conditions, such as chronic fatigue. The extent of the overlap between patients with PS within cardiology and other unexplained syncope groups, continues to be debated in research (Hartman et al., 2004; Richardson & Engel, 2004; Wessely & White, 2004; Nimnuan, Rabe-Hesketh, Wessely & Hotopf, 2001). Notably, there may be consistency across commonly associated psychological factors within PNES, NEAD, and NES diagnosis (Hansen, 2014, 'in preparation'). Therefore, people who refer through the cardiology route may experience similar psychological symptoms to the people who are treated via neurology.

Research widely indicates that younger adults are known to present more frequently with PS; with a prevalence of 79% females (Alsaadi & Marquez, 2005). In PS, literature suggests that patient responses in assessment may present as vague, open to suggestion, frequent events begin without warning, and the eyes voluntarily close during an event so that consciousness may not always be lost (Saal and Dijk, 2014; Dihman et al., 2013).

Importantly, there is no clear evidence-based intervention to date, so healthcare for PS falls outside of the 'No Health Without Mental Health' (DoH, 2011) guidelines for care. However, a study on PNES has found psychological distress, depression, anxiety, and a poor Quality of Life (QL) equal to patients with a diagnosis of chronic fatigue syndrome (CFS), and worse than patients with a confirmed diagnosis of epilepsy (Karterud et al, 2010). Psychiatric

morbidity such as anxiety, is reported to be higher than for example, vasovagal¹⁴ syncope (D'Antono et al., 2009), which may be linked to patients' appraisal of PS symptoms (Rose, Koshman, Spreng, & Sheldon 2000). Research suggests that reassurance for patients with PS is neither sufficient nor satisfactory in alleviating distress, and psychosocial difficulties are widely present, such as interpersonal conflict or unemployment (D'Antono et al., 2009; Linzer, Pontinen, Divine, Grubb, & Estes, 1992). What is more, an unrecorded quantity of patients are reported to cease attending cardiology and NEAD clinics following diagnosis, this may be stigma related (Brignole & Benditt, 2011; Karterud et al., 2009, respectively). To explain this further, it may be that a medical diagnosis is preferred over the uncertainty of a psychogenic diagnosis (Kirmayer, Groleau, Looper, & Dao, 2004). Hence, people presenting with PS are predicted to have poor health outcomes (Huibers & Wessely, 2006; Page & Wessely, 2003).

The aetiology of PS appears to be diverse, for example associative fainting, with the environment triggering past traumatic memories; misinterpreting a threat to self in catastrophic cognitions; a genetic or experiential predisposition to stress; behavioural fainting due to blood injury or family modelling of anxiety, and cerebral-vascular causes such as reduced blood flow (Beck, 1983; Arthur & Kaye, 2000). Aetiological factors to PS may or may not overlap when considering the presentation of PS. For example, an associative trigger may involve subsequent catastrophic thought processes or vice versa, resulting in syncope, or hyperventilation and the fear of blood may coexist as a prime for syncope. The involuntary nature of factors associated within PS appears to be well supported. Post-traumatic stress disorder (PTSD) symptoms such as anxiety and flashbacks, widely known to be associated with social or environmental cues, may be followed by a PS episode, which concurs with associative or diathesis-

¹⁴ Most common type of syncope caused by slowing of the heart rate and a drop in blood pressure, which results in a lack of blood to the brain. This is usually triggered by for example, pain, heat, or shock.

stress. Thus, the aetiology of syncope itself is non-specific, highlighting the heterogeneous nature of syncopal presentations. The heterogeneity of aetiological theories reflects the complexity inherent throughout PS experience. A well-recognised framework to conceptualise complex factors affecting diversity is the biopsychosocial model (Engel, 1980), which demonstrates that physical functioning or behaviour can be influenced by emotional, environmental and psychosocial factors, and vice versa (Reuber, 2009; Vitetta, Anton, Cortizo & Sali, 2005). Also, there may be evidence for neurochemical changes from stress and environmental factors that may influence individual wellbeing (Bremner, 2006).

Relevantly, PS is described as an involuntary mediator of distress, where emotional pain or mental states are translated into symptoms, such as anxiety, enacting through the body and categorized as 'somatisation' (Brown, Syed, Benbadis, LaFrance & Reuber, 2011; Ricardson & Engel, 2004). Given that 70% of patients with PNES reported a history of trauma (Bodde, Kruijs, Ijff, Lazeron & Vonck, 2013), a large body of evidence supports that trauma is strongly associated with somatic illness (Reuber, 2009; Samelius, Wijma, Wingren, & Wijma, 2009; Benbadis, 2005). In other words, trauma expression may be described as disguised information within the body, triggered by unconscious thought processes (Rush, 1996). PS as a phenomena may therefore be further understood using a more embodied consciousness perspective (Boden & Eatough, 2014). PS, classified under somatisation, is widely reported to be a maladaptive form of coping (Steenkamp, Dickstein, Salters-Pedneault, & Hoffman, et al., 2013; Rosenbaum, 1999). In clinical terms, this may mean that a more holistic healthcare perspective is a better way to understanding and managing care (Plesk & Greenhalgh, 2001).

Drawing on historic definitions of 'fainting' (syncope), fainting was attributed to: "Sharp and long afflictions"; "Over great intensesness of thought" and "The suddenness of affliction" (Rogers, 1694, pp.7, 11). The history of fainting as a female 'illness' spans 4000 years (Tasca, Rapetti, Carta & Fadda (2012). By the 1800's, the term 'hysteria' had been well-documented, as had the culturally preferred 'neurasthenia¹⁵' (Tasca et al. 2012). Arguably, either definition associates the mind, as opposed to physiological reasons, with the cause of fainting or physical collapse. Hence, historical explanations of PS may be related to the Cartesian mind-body division in Western philosophy. This division is argued to adversely influence modern medicine with regard to categorising illness, especially PS (Mehta, Zildany, Tavora & Carlos, 2011). Somatic illnesses hold popular acceptability in the East, for example, Traditional Chinese Medicine (TCM), whilst in the West it is stigmatised (Helman, 2007; Kleinman, 1982). Hence, projection of emotion, in the form of somatic expression, appears reliant on the boundaries of social appropriacy and culture (Larkin, Eatough, & Osborn, 2011; Gallagher & Zahavi, 2007). Thus, a more holistic mind-body milieu in the West, may prove useful for PS in Western health care. Notably, the psychosocially based intervention of 'Morita therapy' has been beneficial for neurasthenia-related symptoms such as anxiety, in Japan (Kirmayer, 1984; Morita, 1998; Hoffman, 2008). The therapy has similarities to modern Western emotion-based therapies. The clinical relevance of this is that more culturally transferable interventions could be incorporated in healthcare for people with PS.

A possible consequence of cultural tenets on a micro scale, may be that people diagnosed with PS become casualties of the mind-body dyad and its inherent difficulties. One of these difficulties may be a conflicted conceptual self: the mind which is considered 'reason', and the 'irrational' self of emotion and symptoms

¹⁵ Originally 'organic in origin, caused by for example, stress, bereavement, fatigue, conflict, nerves. It has various degrees of culture interpretation, and became a somatic complaint in the 1800's (Kirmayer, 1984)

(Lakoff & Johnson, 1999; Burkitt, 1999; Lutz, 1988). It is argued that self and society become divided within this philosophy as stigma may be served by the devaluation of the emotions (Burkitt, 1999). This may be in opposition to the phenomenological 'being in the world' (Merleau-Ponty, 1962), where the interconnected mind, body and consciousness engages with its environment on an equal, or holistic basis. This offers an alternative representation to a 'disembodied' self, where emotions may appear in society as ignored, or misunderstood (Leder, 1990). Alternative concepts suggest that emotion needs to be valued as it does not merely impact on society but helps to create it (Gergen, 1994). Also, this appears to assert value to holistic approaches in healthcare.

It has been proposed that language is a neutral expression, whereas it is the body that holds or expresses emotion (Bakhtin, 1986, as cited in Sullivan, 2007; Wittgenstein, 1963). In other words, behaviour 'is' emotion as recognised by body movement, or lack of behaviour for example, in depression (Wittgenstein, 1963). Expression of emotion may be limited by society, and the physical and social body are argued to be at odds within social boundaries (Douglas, 1973). Indeed, boundaries toward emotion suppression grew from the Renaissance period with restraint of emotion in public (Burkitt, 1999). This may allude to 'homos clausus': the 'closed body' and Western cultural individuation (Dépelteau & Landini, 2013). This may have had particular consequences for females as will be seen. Perhaps, as suggested by Nichter (1981, 2010) that although the body appears restrained in its expression of emotion, it finds ways to 'insist' on releasing it.

The adverse physiological consequences of emotion suppression are well recognised (Levenson, 2003; James, 1890). With regard to the 'closed body', the acknowledged prevalence of females in PS is commonly reported to be linked to sexual or emotional abuse or trauma. As it is recognised that females are known to internalise anger or pain, due to socio-cultural factors, PS may occur as a result of

such unexpressed emotion (Sahaya, Dholakia & Sahota, 2011). Equally, anger suppression may be linked as a mediator in trauma, as commonly associated with PS (Luterek, Harb, Heimberg & Marx, 2004). Specifically, negative emotion expression may be culturally determined as characteristic in females (Lester, 2013; Ussher, 2007). To explain this further, Showalter (1985) argues that female disempowerment especially within the Victorian era, gathered into a 'protest through the body', as a means against role inertia and social restraint. A consequence of this may be that females may have had language suppressed through social conditions, so that body language may be an alternate means of emotion expression (Helman, 2007). Thus, with a culturally 'marginalised or ignored' female role, in personal or social adversity, 'ontological alienation' of the self may pervade (Lester, 2013; Ussher, 1991, 2007; Heidegger, 1962, respectively). In other words, a sense of self and place in the world may be lost.

Hence, the prevalent socio-cultural factors from an extensive period, may explain the prevalence of females in 'hysterical' or currently 'psychogenic' presentations. Equally, this may deter males with PS presentations from attending clinics due to stigma. In support, it is argued that largely due to the prevalence of males initially diagnosed with Chronic Fatigue Syndrome (CFS), CFS became more easily accepted as a legitimate illness (Bock & Whelan, 1993). The clinical implication of this may be that a socially legitimate illness may lead to better acceptance and illness adjustment, which has been found to lower psychological distress for the patient (LaChapelle, Lavoie & Boudreau, 2008).

Anthropological studies may inform us about PS for example, perception of our body and our social relationships may change in traumatic events (Lester, 2013). This may be a means of coping by using iterative "processes of meaning-making that emerge in relationships with others across levels of context and time" (Lester, 2013, p. 754). Subsequently, it can be argued that PS in its aetiological complexity

and possibly culturally divided sense of self, presents a 'back and forth' pattern of engagement with services to seek experiential meaning of, or explanation for PS symptoms. Equally, the lack of illness explanation and understanding of emotion in healthcare may reduce a sense of a self as whole and perpetuate a fragmented sense of self (Yontef, 2005). In contrast, facial recognition of strong emotion is well researched and universally understood, while the language of adverse emotion through bodily expression, and interaction with the environment requires further research.

Having briefly considered the interplay of Western ontological influences, feminist concerns, and anthropology in understanding aspects of PS, a psychological perspective incorporating health beliefs may be useful to frame PS.

The SRM (Leventhal, Nerenz, & Steele, 1984) describes how peoples' perception of their illness or how they make sense of it influences health behaviour or beliefs. The SRM identifies cognitive and emotional dimensions in which people represent or understand their illness, in context of their environment (Leventhal, et al. 1984). Broadly, people make sense of their illness in relation to: illness identity, cause; duration; symptom perception; and locus of control (Cameron & Leventhal, 2003; Baumann, 2003). For example, in the case of PS, terms such as 'attack', 'disorder', or 'psychogenic', may introduce or reinforce negative beliefs in the patient's perception of the illness (Bravo et al., 2013; Stone, 2013). In support, using such terms is currently reported to contribute to social stigma in mental health nationwide (Garand, Lingler, Conner & Dew, 2009; Lutz, 1988). Such beliefs around illness may be interpreted as a sense of threat for the patient (Bravo et al. 2013; Leventhal et al. 1984). Hence, health psychology has utilised metaphors and 'idioms of distress' as a means to provide deeper meaning to experiences emotionally, and aid recovery through interpreting language (Nichter, 2010; Shinebourne & Smith, 2010).

On a wider scale, health beliefs are dependent on information sourced from family, friends, and indeed society (Hagger & Orbell, 2003). These social spheres of influence may impact on whether beliefs are positive or negative, and may be assimilated into personal experience and expression of illness (Leventhal et al. 1984). Importantly, direct links have been identified between health beliefs in MUS and attending services or treatment, and 'illness-perception based interventions' are being developed (Petrie & Weinman, 2012). For example, if the patient considers that they have no control over their syncope, interventions could target self-management behaviours which may increase a sense internal control. Further to this, if maintenance of PS is related to negative social discourse, new information may offer a more positive dialogue into the patient's perception of PS (Petrie & Weinman, 2012).

As commonly reported in literature, a lack of an illness representation may lead to poor adjustment to illness and poor coping with consequent anxiety, depression or lack of social support (Valente, Rebeirio & Jensen, 2009; Baumann, 2003; Moss-Morris et al., 2002; Leventhal et al. 1984). Notably, there is evidence for adverse bio-physical effects from social isolation in chronic conditions (Karelina & DeVries, 2011). This concurs with findings in literature for chronic pain, where poor adjustment to illness may lead to impaired recovery for the patient (Valente, et al., 2009). Importantly, chronic conditions may have inherent psychosocial difficulties such as isolation, which also may lead to poor adjustment (Valente et al., 2009; Leventhal et al., 1984). The prevalence of psychosocial difficulties or poor adjustment to illness comparatively for people diagnosed with PS, and their families, remains unclear.

Finally, if patient's beliefs about their illness can be understood, then specifically targeted interventions may improve health outcomes. There remains a gap in the literature regarding how the individual conceptualises psychogenic syncope

(D'Antono et al., 2009). Equally, the vast amount of literature appears to be quantitative to date, so patient perspective around PS may be gained through qualitative investigation. This study aimed to explore the meaning to individuals of a psychogenic syncope experience and diagnosis, to gain insight into their world and needs.

Therefore, the primary research question was:

What are the experiences of people diagnosed with psychogenic syncope?

2. Methodology

2.1. Design

Qualitative methodology and analysis via Interpretative Phenomenological Analysis (IPA) was employed. This method explores in depth participant's experience and the meaning of having psychogenic syncope, using a semi-structured interview process. Qualitative data collected from interviews were transcribed verbatim by the author, and subject to interpretative analysis.

2.2. Participant characteristics

Overall, six female participants recruited from a convenience sample at a cardiology syncope clinic at a Foundation Trust, North West England, took part. The patients had all received a confirmed or probable diagnosis of psychogenic syncope by the senior syncope Sister. The sample were working age adults between 18-65 years old, the average age was 35.5 years old. All were fluent English speakers. A total number of 31 patients, five male and twenty six female, who met the inclusion criteria were informed at the clinic, or through the post, about the study by the direct care team. The prevalence of females in total, concurs with literature (Alsaadi & Marquez, 2005).

Of the twenty five participants who did not take part, eight were Asian British, four male and four female. Of the six participants that consented, one reported a mixed diagnosis of low BP and PS, and two reported being unclear about their diagnosis. One participant reported recently recovering from PS. A recent bereavement was reported by three participants, experienced within a range of one to four years. One participant reported experience of verbal abuse, and one reported physical and sexual abuse, and an eating disorder. In accordance with existing literature, a range of these experiences have been reported in PS (Bodde, et al, 2013; Reuber, 2009; Mökleby et al., 2002). The majority of participants reported that despite having a supportive partner or a family member they did not understand a PS event. Interestingly, one participant depended on wider social support and the kindness of strangers. Notably, a supportive network may have been the exception, due to the majority of literature reporting interpersonal difficulties in PS (Linzer et al., 1992; D'Antono et al., 2009). Psychosocial difficulties, or adverse life events, were reported by participants, such as interpersonal relationship conflict, relating to neighbours, unemployment, and environmental issues. These experiences are reflected in literature that widely reports psychosocial difficulties in this patient group (Karterud et al., 2009; Reuber, 2009; Linzer, et al., 1992). A large number declined or were not contactable (n = 25), the reasons for this are shown in Table 1.

Table 1. *Reasons given for declining the study invitation*

1 Work related
3 Stated not having psychogenic syncope
2 Reported feeling better
3 Initially agreed, then cancelled
2 Postponed, then cancelled
3 DNA* arranged interviews
3 Disconnected telephones
1 Reported too scared to talk about it
4 Did not return a call after expressing interest
3 Declined outright

Total n = 25

*Did not attend (DNA)

In total, six female participants consented to take part. Table 2. shows the participant's self-reported demographic information. Participants identified as White British: (n = 5) and Asian British (n=1).

Table 2. *Participant demographic Information*

Pseudonym	Fiona	Maisie	Sharon	Debs	Flo	Pam
Gender	F	F	F	F	F	F
Age	25	44	56	49	18	21
Time since diagnosis	1wk	7m	5yrs	3yrs	3m	2yrs
Age at diagnosis	25	44	51	46	17	19
<hr/>						
HADS						
Anxiety	16	21	16	8	6	8
Depression	7	12	7	6	4	2

2.3. Measures

Participants were requested to complete the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) (see Appendix J) prior to the interviews. It was employed to describe the sample, by assessing the presence of depression or

anxiety. The results of the HADS informed analysis by accounting for contextual information in interpreting the findings.

Semi Structured Interview: The SRM has been used successfully in health psychology IPA studies, to explore people's sense-making of illness (Brocki & Wearden, 2006; Leventhal et al. 1984). A semi-structured interview based on guidelines from Smith and Osborn (2007), incorporated the framework of the 'Brief Illness Perception Questionnaire' (BIPQ, Broadbent, 2006) based on the five components of the SRM (Cameron & Leventhal, 2003) (*see Appendix E*). The components were structured under question headings and included the participant's illness perception, the psychosocial effects of their condition, their perceived control, and thoughts on causes of their condition, as well as having a psychogenic diagnosis. The questions were designed to provide insight into, not a measure of, how participants' perceive and experience PS. Furthermore, insight into participants' experiences, guided by an established framework, may help to conceptualise a complex condition and consequently identify interventions in the process (*see Figure 1*). However, participants described their experience of 'blackouts' from open-ended questioning, which allowed for a participant-led direction or diversion from the question in their responses.

Throughout the interviews the term 'blackout' was employed because it was used within the syncope clinic and hence familiar to participants. Also, it was used in an educative leaflet offered to patients by staff, once diagnosed. The aim of the study was to hear the participant's voice and their description of the blackouts. Prior to recruitment, interview questions were piloted with the direct care team, and an outpatient at the clinic, to ascertain suitability of questions to see whether they would elicit description, and talking about, experience of syncope.

2.4. Procedure

Ethical approval was obtained from the local Ethics Committee (see Appendix F). Information about the study was offered to potential participants by the direct care team. Retrospective participants were identified through clinic records, by the Sister, and a poster, information sheet and a covering letter were posted, informing them about the study. If the participant expressed an interest in the study they could email or telephone the researcher directly, or leave their name and contact number. The researcher contacted those who expressed an interest to provide further information, and to encourage participants to speak to friends and family about the study, if they wished. Consent was gained prior to the interview, which was undertaken at the clinic, or at the participant's home, according to participant's preference. The six participants that gave consent all expressed the wish to be interviewed in their homes. Potential participants who requested a hospital location for the interview, did not attend as arranged, or cancelled. The length of the interviews were on average between 45 minutes and 60 minutes, guided by the participant, and audio-recorded. Anonymity of the participant was confirmed by the researcher prior to interview. Pseudonyms maintained anonymity during the analysis. Following the interview, participants were offered future feedback on the main findings of the study, if they so wished.

2.5. Data Analysis

The data was analysed following guidelines from Smith, Flowers, and Larkin (2009) and taking into account pertinent articles. The data was transcribed verbatim by the author to allow for immersion in the data. A critical aim of the analysis was to obtain a rich data set by reading and re-reading the transcriptions for total immersion, with significant and interesting semantic language highlighted. The transcription was divided into initial comments, concepts and description of the content, checking for

emerging themes and organising sub-headings, and super-ordinate themes to a main cluster between the entire data set. The identified themes were checked for patterns. The transcripts were read by four independent researchers to evaluate content, comment on emerging themes and maintain analysis quality. Reflective analysis was employed by the researcher, and deconstruction techniques, in an attempt to bracket out the researcher's impact upon the data (Smith, et al. 2009).

2.6. Quality and validity

The second and third author reviewed and discussed the data and the emerging themes in an ongoing process. This occurred in order to keep the themes grounded within the participants' verbatim. Peer review by two people with experience of research in IPA, enabled further credibility to the analysis. The analysis of themes in this study employed intuitive interpretation of verbatim, which had a resonance across the participant's descriptions (Smith et al., 2009). There is limited research that utilises metaphor in language, in order to explore the complexity of emotion (Nussbaum, 2008; Damasio, 1996), so the use of metaphor will be briefly explored in the analysis of this study.

3. Results

Seven subordinate themes, and five super-ordinate themes that emerged from the data are shown in Table 3. The HADS (Zigmond & Snaith, 1983) profile of participants appeared to indicate that depression was normal across five participants and moderate in one, unlike the prevalence reported in literature. This may possibly be explained by the participants' support reported from family, which may reduce depression in illness (Valente, et al., 2009). However, raised anxiety levels were present across participants at the point of interview. This supports current literature which demonstrates prevalent anxiety within this patient group

(Karterud et al. 2009; Rose et al. 2000). To note, Maisie who appeared to have the highest levels of depression and anxiety reported the least social support.

Table 3. *Super-ordinate themes with corresponding sub-ordinate themes.*

Superordinate Themes	Subordinate Themes
Disconnection	Mind-body separation (6)*
Uncertainty	Scared (6)
Dissociative	The cul-de-sac of collapse (6) Three (wise) monkeys (6)
Battlefield	Fighting (4)
Identity	Abnormal (5) The Shelved Self (4)

*Number of participants' accounts in which the themes emerged

The experience of blackouts appeared to impact on participants on a daily basis; in the sense of overshadowing every aspect of their lives. The themes relating to the participant's experiences appeared to be reasonably homogeneous throughout the data. The term 'blackout' is used to represent the participants' language.

Super-ordinate theme: Disconnection

Mind-body dualism appeared to be reflected in the descriptions across participants' accounts, with confusion around the meaning of diagnoses, and the lived experience of PS. Mind-body separation emerged as related to participants feeling disconnected from themselves, which participants observably emphasized with an intonation of frustration and a sense of helplessness.

Mind-body separation

All participants expressed a strong sense of the brain being separate from the body, a fragmented sense of self. Fiona, Maisie, and Sharon described the mind as separate from the body by reference to: *'it'*, and *'brain'*. This may be due to the medical model in illness, and a paucity of explanation about the interactions of the mind and emotions for the patient. There appeared to be a general sense of a lack of control over the brain for the participants.

An inherent helplessness against what was felt like an alien entity:

Fiona '...because my mind does stuff that makes my body do stuff that I don't even know how to stop. My brain just wants to do whatever it wants and I'm just tagging along behind really. It's like my brain and my body aren't, aren't together, like I don't know how to explain it, your brain's powerful and it does stuff that you don't realise its doing....if your brain can make your body physically have a fit, what else can your brain technically do?'

Maisie '... you don't really control them (blackouts) because it's not actually you that's doing it, it's your brain'

Sharon '... it's like someone's took over your body, I know it sounds weird'

The following metaphor was used in the context of the brain *'doing stuff it shouldn't like blackouts'* (Fiona) and offers a strong image about the sense of a struggle with something stronger than you and at the same time *'in bits'* (Fiona).

Metaphors related to the sense of disconnection.

Fiona: 'My brain 'boots me up my backside'; 'For the last five years my 'brain has been in bits'

Superordinate theme: Uncertainty

All six participants keenly described being scared as one dimension of living with blackouts. All of the fears appeared to be associated with uncertainty around not having a clear understanding of blackouts, and the anticipation of when they might occur. Being scared of the blackouts, or the unknown, as a subordinate theme related to the environment, blackout unpredictability, and vulnerability with others in social situations. To cope with feeling scared participants described having to plan when to go outside, or avoid going out if not accompanied. Equally, there was a sense of embarrassment with a blackout occurring in public, with some participants.

Scared

Going out alone due to uncertainty of a blackout, and unsafe environment

Pam: '...it is really petrifying, the unknown, It's scary, unknown, I'm lucky to feel it before it's gonna happen. Scared because you don't know if you're going to wake up. I know it sounds stupid now and I panic am I going to wake up, where am I gonna be, who's gonna be there, not knowing, paralyses me, if someone seen me blackout and took me'

Sharon '... it needs to stop, and it, it does scare me a bit, because, er, like I say, if I was somewhere where nobody knew me and I had one, nobody would know what, what to do'

Fiona: 'I won't go out, because I think oh my god if I have one, you know, no, you know, no one, I'm not with anyone that knows me, I'm thinking, you know, someone might rob my bag while I'm having one'

A sense of shame or embarrassment in public

Maisie '... scared I think it's because I, you don't know, or all the time you don't know it's going to happen, and that's what it is, and, er, scared that I'll show myself up and show other people up, I say I'm really sorry, I feel so embarrassed'

Sharon '*... I'd think oh, come on, get up, come on, I can go, and, you know, do a runner, like when you fall outside you think oh, scared I've shown myself up*'

Medically related illness, or somatic complaints, were mentioned in the search for certainty, and alleviating feeling scared.

Fiona: '*My kidneys have been hurting for a, er, a good couple of months, and now I'm debating myself are they actually hurting or am I making it up now, because if your brain can cause your body to do that without you knowing. I'm uncertain, pretty much about everything now. Someone telling me that I had epilepsy and this, I would have been happier with epilepsy, I probably wouldn't have been as scared*'

Pam: '*My friend's sister-in-law has epilepsy and she blacks out, it's not so scary*'

An idiom which highlighted contact with services, may have enhanced the participant's sense of uncertainty through feedback from the environment:

Metaphor describing health services being uncertain about PS

Fiona: '*...If I go say to another doctor ah, they say, I don't know what you're on about. The doctors are left scratching their heads*'

Superordinate theme: Dissociative

Literature has widely debated dissociative experience within psychogenic syncope, as to whether consciousness is lost. Two participants appeared to completely lose consciousness, and four discussed awareness at some level during a blackout.

There were narratives which highlighted confusion and contradiction around loss of consciousness. Nevertheless, it appeared that participants may have collapsed as part of a dissociative experience, possibly from reported trauma, and observable psychosocial and environmental stressors.

The two subordinate themes gathered from participant's accounts were 'The cul-de-sac of collapse' and 'Three monkeys'. Participants' accounts of collapsing described what a blackout felt like, which appeared for some to be a sort of relief from fighting or exhaustion, in a cyclical process. Equally, participant's articulating of 'collapse' (Sharon) or 'fall' (Maisie) may indicate a different experience from the term 'blacking out'. Throughout there was a sense of 'going nowhere'; a cul-de-sac. With regard to the 'Three monkeys', it became apparent during the interviews that six participants highlighted seeing, hearing and speaking, as an important part of their blackout experience. It can be argued that a major part of a loss of consciousness, and being believed as to whether a blackout is genuine, is related to whether the patient can see, hear or speak.

The cul-de-sac of collapse

A number of factors presented themselves within the accounts related to collapsing. Firstly, assimilated into the process of 'falling' was the feeling of being drunk, before or after a blackout occurred. It was alluded to within the narratives by three participants, and was felt to be a useful descriptive adjective, as collapsing may be associated with drunkenness. However, participants reported that they did not drink alcohol, collapse may have been exhaustion-related.

Maisie: '... I've started walking like I'm drunk now. I have to hold onto things as I'm walking. I don't drink; I walk like I'm drunk sometimes. So, getting confused and, er, um'

Debs: 'And I'd go, if I was out and, er, say I was in a supermarket or something I would just go as if I was drunk. Because I don't drink anymore, I stopped drinking when all this started. But I, I never drunk a lot anyway, but I just thought I don't want to have that feeling on top then if I go off, so I don't drink. But the only way I can explain it is like as if I'm drunk and I'm walking drunk'

Flo: *'I don't drink, I don't remember anything, blackouts not scary it's more I don't remember and wake up not know anyone, my speech gets worse, slurred when coming out of it. Like I'm drunk'*

As well as a felt sense of 'letting go' within having a blackout, stress appeared related to psychosocial and emotional factors and the tiredness woven from stress, all appeared to play a part in the build up to collapsing. Conscious awareness is apparent apart from one account, and breaks of consciousness in others.

Fiona *'... your body'd, er, like a relief in blacking out, because you're getting too much, like too much emotions, stress, I were just falling asleep everywhere. You're awake but you can't do anything and you can't stop it, and it's just releasing. I know what's going on around me, um, pretty much it'*

Flo *'I came down the stairs, and came in front room but I couldn't understand how I got downstairs, like it's hard to work out which, tripping over or falling over coz I'm tired'*

Maisie *'...and I remember being, and being confused, um, and really weak and feeling like I hadn't slept for probably five years, you know um, really tired and exhausted and just feeling, like basically I've got no strength and that's it, you just let go and you just fall'*

Within collapsing are the symptoms associated with 'blacking out', two symptoms appeared consistent across four participants: dizziness and the sensation of heat. Anger may have been observed within the intonation and gesticulating expressions of four participants. Equally, there appeared to be warning signs before a blackout and a sense of control for some participants, contrary to literature.

Sensations and emotion during episodes of blackouts

Sharon: *'Er, well, er, I, I knew I were getting very warm, and I felt a little dizzy, you know not knowing, as if I was actually here. I feel*

very anxious, out, I get out of breath and I've got that very warm, I get so hot and that, and flustered and that, and I need to, um, get someone to come and pick me up'

Debs: 'Sometimes I would go really hot, and just really, really like cotton wool headed, really, really, really lightheaded and then just, but I knew I was going, I'd got signs I were going. I just, it feels, I just, sometimes I go hot and just really, really dizzy, really dizzy'

Pam '...once that feeling's got up to my chest, sounds stupid but it's like a warm tingling feeling rises can feel it in my feet, legs feet first then rises, it never goes past my chest ever or if it has it's already hit me I've already gone'

Warnings, and a sense of control by stopping or pausing for breath.

Debs: 'I'd think right I'll go and sit down, and just sit quietly and hope it passes, and just sit for a few minutes then it would pass'

Pam: '...horrible it is horrible (emphasis) don't know if you gonna wake up, cut your head open, that's why if I feel it I just lay down, wherever I am, hopefully not outside, but wherever I'll just lay down'

A number of participants described how they felt about going to services with a sense of frustration about services being unable to help

Debs: 'But it was always the same because I was under Dr S, and cardiology there was, there was nothing they could do. I was distraught, absolutely distraught and scared, I had just had enough, I said it's like everybody else is saying right everything's fine, I said but I'm not fine. Nobody knew what to do, but there was like nobody out there to talk to'

Fiona: 'Er, that were from my GP, at my doctors, with the blackouts, they weren't quite sure what were wrong'

Sharon: 'I were put on the sick. Well, I kept collapsing quite a few

times at work. Um, I kept going to doctors, and when I went to doctors, oh you're alright, there's nothing wrong with you. Um, I mean alright I did feel tired, I must admit, I did feel tired and what have you, but he said there doesn't seem anything wrong with you, so they took no notice of that'

One metaphor related to collapsing offers an image of falling, and another describes the feeling in relation to a dissociative experience.

Pam: 'I seem to always go backwards I just fell down as a 'sack of potatoes'

Sharon: 'Because blackouts, er, I mean they were, er, as if you're 'neither here nor there''

Debs: 'A nightmare, it's just a black, black, really black, black hole, just not nice'

The first metaphor 'neither here nor there' can arguably be relational to a description borrowed from Foucault (1984) regarding 'other spaces', in which he discusses the 'partitioning of human life' where 'creating a space of compensation' is necessary due to chaotic lives. Thus, it may be inferred from the participants' accounts that the 'space' from a blackout, may signify a relief, '*I don't remember*' (Flo), or '*exhausted*' (Maise). More so, the '*black hole*' (Debs) metaphor may symbolise a sense of self that has been deconstructed from an absence of a mental representation of PS as an illness (Wisdom, et al., 2008). Equally, possible that a 'compensatory space' may parallel with '*let go*' as absence of stress or emotions. For example, grief: four participants had experienced varying forms of bereavement or loss. Equally, there were accounts of psychosocial role losses such as loss of employment and social activities.

Parallel with a felt sense of being unsupported, there was common ground across accounts about what participants thought would help them out of the 'cul-de-sac'. Casualty services was a common reference point mentioned by participants. All

had experienced visits to casualty via ambulance, due to a blackout. Pam spoke about the relief of a diagnosis related to a possible medical cause, and Sharon spoke about feeling relieved that it was not her *'doing it on purpose'*. Notably, *'on purpose'* may signify other peoples' admonishment.

A way out of the cul-de-sac

Fiona: *'... there isn't really anything, information for people like us. I'd like someone to sit down and explain to me, instead of reading a booklet, explain to me. Because she said ah, it's emotion and stuff like that. Well yeah, I know that, but what else? You know, there's obviously more to it than –'oh, it's your emotions', it's stress, you know, there's got to be a bit more about it, your brain must be doing something. So I think like just explaining like, explain it a bit more in depth I think, because instead of, you know, do you get what I mean, because she said it's like, built up and then you've released it. Well I understand that, but why is it building up, you know, what can I do to stop it from building up?'*

Flo: *'I get ignored by [casualty], so it's nice to have an answer [diagnosis] be believed'*

Debs: *'...it would have been nice if there'd have been more support, or advice, just advice, but I felt like you're just, right, you know, you've done this test, crikey, I did tilt test, this test, other test and it's just... she [GP] said even if you just go and just have a chat with cardiology. Um, it would be nice, when I say support groups, if there was just somebody, just a nurse that you could ring''*

Three (wise) monkeys

The analogy of the three monkeys seemed appropriate as a subordinate theme in relation to the emphasis of the participants' accounts in reference to the communicative senses. Shame and embarrassment were mentioned by a number

of participants in respect to closed eyes. In support, 'not seeing' is alluded to as hiding or defending oneself from shame, in psychodynamic terms a form of denial or repression (Adamson & Clark, 1999 p. 43). Equally, alluded to is to 'can't look' (Fiona), which may stop the perception of something that may be disturbing if acknowledged (Thompson & Cotlove, 2005). Tentatively, aspects of selective mutism may parallel 'seeing and hearing' in PS; with similar reported emotions related to anxiety, trauma, conflict, and anger displacement (Wong, 2010).

A voluntary inability using the intentional verb 'can't look' (Fiona) as opposed to 'can't see' (Maisie), and a sense of having partial vision was described. There appears to be accounts of partial speech relating to 'coming round' or 'slurred' after a blackout (Flo). Accounts describing 'not remembering' (Debs, Maisie) but of being able to hear, and 'can't say' (Fiona) may be contrary in terms of intention, of loss, in ability to speak.

Fiona: 'While it's happening, but as I'm doing it, I can't say anything, I can't look at anything, but I can hear everything. So like I could... I'm like I can hear, I can hear the TV and I know my partner's helping me because I can hear him helping me. I just can't say anything'

Maisie: 'I can't see properly... I collapsed. I felt like there were black [emphasis], blackness coming to my eyes, in front of my eyes and everything was spinning and, you know, and my ears were going, you know, there's a noise in my ears and then next thing I'm on the floor. ...I can't remember being on the floor or being unconscious or whatever, but somebody was telling the paramedic that she was sort of shaking a bit as well'

Debs: 'I just do not remember. I just remember paramedics on the floor, by my side. I could hear. Yeah. I couldn't see, I could hear. It's like I could hear things in the background but I couldn't, I couldn't say anything. I don't remember anything because I could just hear sirens and then I could hear muffled voices'

Interestingly, a possible means of avoidant coping to not think about blackouts, was described by one participant as 'not writing'. A possible means of avoiding the reality of blackouts.

Sharon: *"I can't write stuff down, cause it makes it too real, it's in black and white then, you're thinking about it, ...and it is upsetting"*

Superordinate theme: Battlefield

Battlefield emerged as an overarching theme that contained the subordinate theme of fighting. The battle appeared to encompass a number of areas, namely the sense of self related to blackouts, beliefs around them, and psychosocial issues.

Fighting

In the first example, the dimensions of fighting appeared to pertain to a struggle related to the sense of mind-body disconnection. The blackouts appeared on one level to offer a respite from fighting. Sharon tried to combat blackouts by self-statements, which were both negative and positive, she coped by trying to avoid the reality of her experience. Whereas Debs expressed frustration at not understanding the blackouts and fighting with herself in the process.

Fiona: *'I just get on with what I do, er, nearly every day, is argue with myself to get out. I fight with my brain. There's two voices in my head going, you know, accept it, don't do, do, do, do, and it's like, you don't. Um, it's just more like, like at the moment it, it's like because I've spent so long fighting to go out, ...it's a constant battle with yourself, ...and you're just arguing upon yourself, in your own little head'*

Sharon: *'Um, um, I think it's when that's going to happen as well, because I'm, er, I try to fight it, you see, well it's not going to happen to me, I say I'm alright, don't be so stupid. But I think that's me trying*

again to not believe that it's happening, to try and defy, you know, combat it, oh, I can do it'

Debs: 'I would go outside and mow the grass and just think if I'm going to, bring it on. If it, I'm not going to, it's not going to beat me. I just felt myself just dipping but I didn't understand why and I've kept trying to fight it off, was beating myself up'

An idiom expressed by Fiona, illustrates a sense of onslaught, the separateness of the blackout from a sense of self, by using 'it', and a sense of 'wanting to understand'.

A sense of continual struggle

Fiona: '...you just want it to stop really, you just want it to 'pack it in' really, and you just think, you know, what's happening?'

Superordinate theme: Identity

The dimensions of identity are under the two subordinate themes of 'abnormal' and the 'shelved self'. Abnormal was described with regard to not being understood because blackouts were not medically known, and awareness of looking stupid or sounding stupid as a consequence. The 'shelved self' related to comparison of the old functional self to the current 'stopped' or stuck self. This appeared to be consequent to lacking a recognised diagnosis, the loss of identity. From this a sense of disempowerment evolved through the participants. Disempowerment engendered itself through descriptions of feeling 'weak, helpless, weird, confused, or stupid', as well as a sense of a lack of control to return to 'normal'.

Abnormal

Abnormal became apparent in repeated patterns throughout accounts, concurrent with a strong sense of difference from others. This appeared to be mainly due to

not understanding the experience of PS. Fiona's account of *'not meant to'* may possibly be socially related to others' understanding of an undefined illness. Equally an ongoing sense of disconnection from the self, appeared to be present and feeling different and *'stupid'* (Fiona, Maisie, Debs, Pam) in comparison to others.

Fiona: *'Um, I get sorted, and then, um, I'm quite a poorly person like. Yeah, and you're just, surprised I'm not crackers really. I probably am [laughs] but it's just you're not meant to have blackouts, unless there's something medically wrong with you, everybody I've said it to, not once heard it'*

Sharon: *"But then you get this feeling, er, what am I s, such a stupid idiot, this feeling comes into your head straight away, oh you stupid idiot. Because how can you be doing this, why isn't anybody else doing it?"*

Debs: *'Because I think well I am stupid, why, why do I just feel like this at certain times, and I know it sounds really idiotic, felt I wasn't normal, it's not like it's a cancer or anything, so I wasn't ill, ill, I just didn't, I felt like this person that wasn't right, and, and I wasn't in control. I felt all the time like I was some sort of freak'*

Pam: *'No I just go out, still it's a weird feeling, sounds stupid. You feel not normal, it's like someone's took over your body I know it sounds weird'*

Shelved self

Prior to blackouts, a few participants reported being in full-time employment, enjoyed their jobs, had active social lives, and self-confidence. It was felt that blackouts changed their identity to a sense of *'not back to me'* (Debs), with loss of work, friends, and activities with family, and consequently confidence, resulting in inability to leave the house in some cases. Three of the participants expressed this loss emphatically with frustration and anger, and a sense of missing the old self.

Debs speaks about a sense of change and loss in professional identity. 'Shelved' as parallel to 'stuckness', may be a lack of adjustment to illness by being unable to accept PS as a diagnosis, possibly due to a lack of a representable illness (Valente et al. 2009; Moss-Morris,2002). A consequence of this for people may be the inability to move forward, adjust and recover (LaChapelle et al. 2008).

Sense of loss of a past identity.

Fiona: 'Yeah, all like that I never followed anyone, was confident, I did my own stuff, I always have done'

Sharon: 'It's not being, not nice being tired, because I've always worked, I loved, it was something I liked doing because I kept meeting people. Being tired and not being able to do things what you're used to doing, er, and just going out, er, at drop of a hat, thinking oh well, oh it's nice today, I'd like to go out, I can't do it like I used to, because my confidence has just gone so down'

Debs: 'I've never just sat in a chair and said I don't feel well, I'm not going out. I think the, the effect of it, it was more, I was going more introvert and I was losing my confidence Because everything, it just seems like somebody's stopped, pressed a pause button and everything's gone on hold. One minute I was this professional person, a good social life. I just thought let me get back into work. I started getting mad, really mad with myself. So then I, I've sort of taken a backseat thinking. I mean when I was going to see cardiology, um, I looked awful. I felt awful. Um, but I'm still, it's like I'm still not back to me yet, back into a job that I really love'

Idioms and metaphors highlighted as a strong sense of a 'shelved self':

'Someone's pressed a pause button' 'On hold' 'Not back to myself' 'I've taken a backseat' 'Out of the limelight' (Debs) 'Used to do... at drop of a hat' (Sharon 'It wrecks your life' It pulls you back from trying' (Fiona),

The above descriptions reflect a profound sense of change in and a loss of previous identity, social activities and roles.

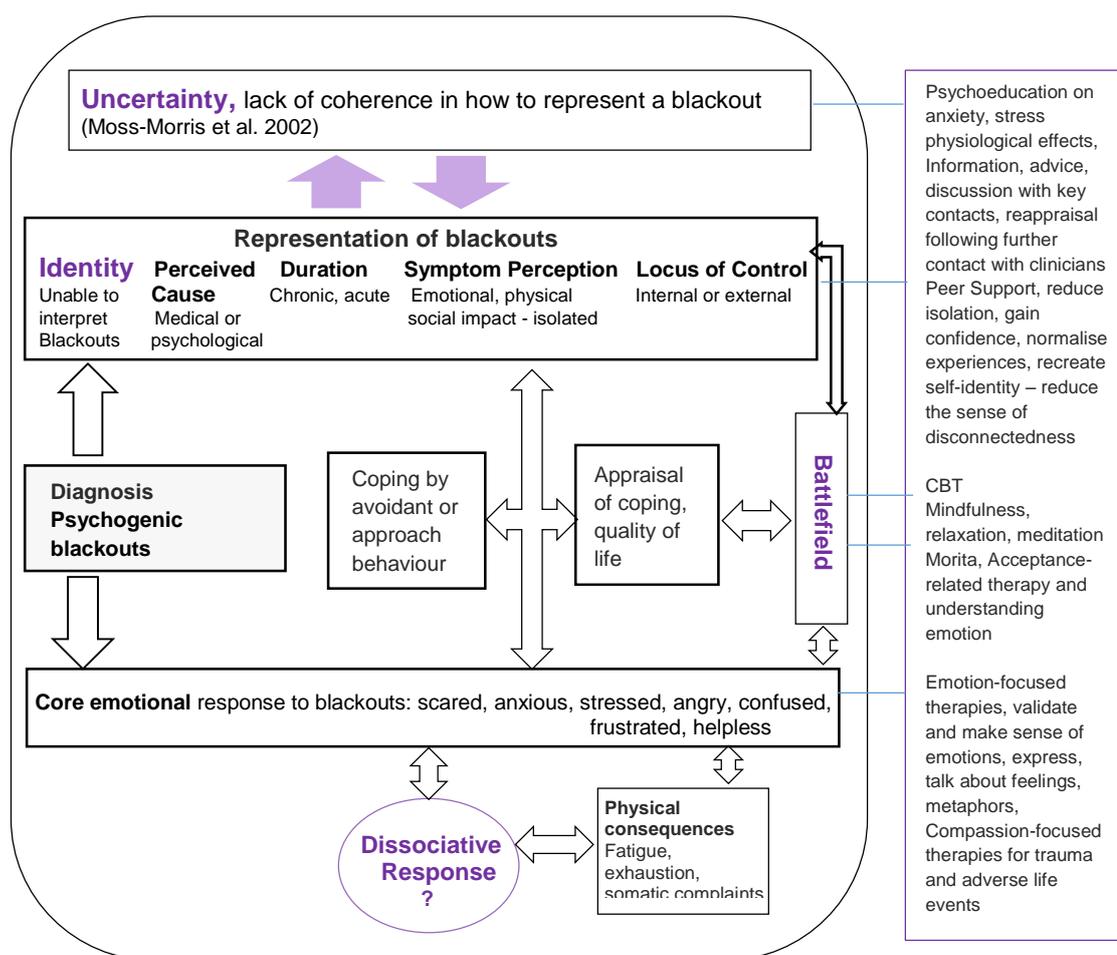


Figure 1. Participants' experience of PS, adapted from the self-regulation model (Leventhal, et al., 1984) incorporating themes where possible from this study, and highlighting possible interventions.

The theme of uncertainty in participants' accounts may correspond with the lack of a coherent illness representation in PS (Moss-Morris et al. 2002). This may explain the participants feeling 'scared' of the unknown, disconnected: '*All in my head*' (Maisie), '*Am I making it up?*' (Fiona), with the overall sense of a mind-body separation. Equally, as described, a 'felt' difference compared to others may have been due to not having a socially understood illness, which may have led to some participants feeling isolated (Charmaz, 1983). In other words, having an illness that is not representable in the outside world. Indeed, a sense of stigma was described

across participants with: *'I'm crackers'* (Fiona), or *'I'm stupid'* (Pam). A lack of understanding may in turn have contributed to a deconstructed sense of self-identity and self-belief (Cameron & Leventhal, 2003). To expand on this, the participant's 'outsider' or 'shelved' role in society, may resemble a sense of liminality (Willett & Deegan, 2001). For example, the experience of a disconnected, less confident self or *'professional'* (Debs) identity and uncertainty, may be described as liminality. A state of liminality, a transitional stage for the individual, is considered to be anxiety provoking, due to uncertainty in the loss of or change in a social role (Thomassen, 2014). Equally this has been described as 'stuck' with the apparent difficulty of participants adjusting to PS. Indeed, as reported in literature, participants had significant life stressors such as bereavement, illness, and psychosocial issues (Valente et al., 2009; LaChapelle et al., 2008). A lack of adjustment appeared to parallel with the presence of anxiety as reported in literature (Valente et al., 2009).

In regard to perceived cause as literature suggests, a medical diagnosis appeared to be preferred over a psychological one (Langfitt, 2007). In support, this was alluded to with: *'I'd have been happier with epilepsy'* (Fiona). Also, participants may have been actively seeking a medical cause, with descriptions of *'kidney pain'* (Fiona) or *'head injury'* (Maisie), and frequent hospital visits. Overall, participants reported uncertainty about the duration of PS.

Perception of the emotional impact on people was described as scared, anxious, or stressed, with observed anger and frustration. The physical impact was described as fatigue or exhaustion, with possible somatic sensations such as heat, dizziness, weakness, headaches, or tingling sensations. The social impact appeared to be isolation, as a number of participants reported being unable to go out of the house independently, work, or socialise as they used to do. This appeared to amount to

an overall 'felt' sense of loss for some participants. This could have added to possible bereavement experience for some participants, and a sense of a continuum of adverse events as reported in literature (Bodde et al. 2009).

Finally, locus of control appeared to be external, with some participants describing a feeling of being 'out of control' (Debs Maisie, Fiona, Sharon). However, there appeared to be an ambivalence around coping with both avoidant and approach behaviour. For example, at times participants reported trying to find answers, or use positive self-talk '*I can*' (Sharon) to get better, possibly to regain an internal sense of control. Whereas, coping by avoidance, meant for example, not going out, or '*not writing it down*' (Sharon) so as to '*not to make it real*'. Arguably, in light of this, PS appears to be a bewildering and harrowing delegitimised condition in its current form of classification.

The theme of battlefield appeared to correspond with accounts of struggling with the various symptoms, and to understand what blackouts were, with both mental and emotional struggles to contend with. Critically, a sense of battle suggests that people may not accept their illness possibly through the lack of an explanatory model for PS. It is reported that acceptance of an illness may lead to improved health outcomes (LaChapelle, et al. 2008).

The participants' emotional struggle may link into their mental state and perpetuate the overall sense of a constant battle, leading to physical tiredness (Reuber, 2009). There was a sense of emotional confusion in participants' accounts, and an apparent lack of ability or control over their senses. Subsequently, this array of mental and emotional striving or exertion may increase sensitivity, possibly through exhaustion, to a dissociative experience in which thereby a cycle is maintained.

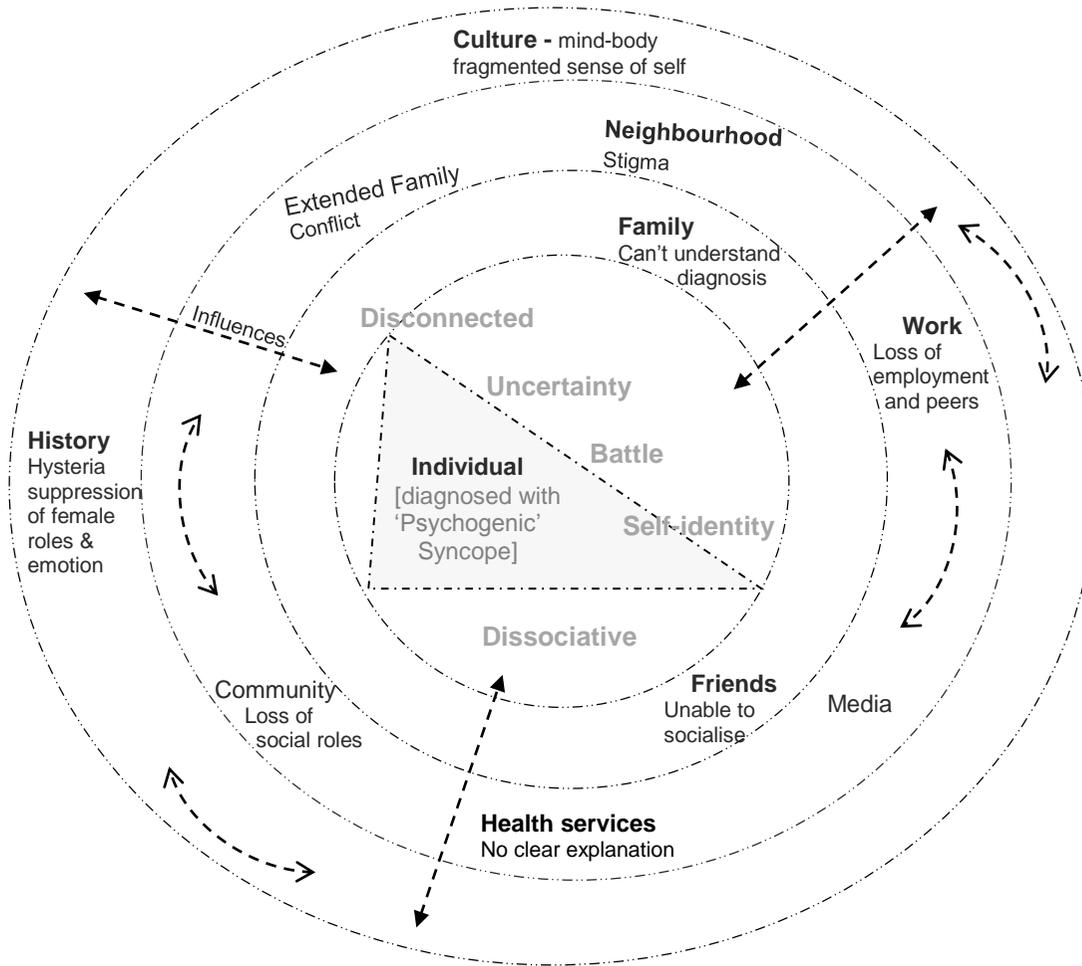
This has parallels with literature, which suggests that a dissociative experience may be a maladaptive coping style, in order to diminish personal, emotional or social

distress (Brown et al. 2011; Beere, 2009, respectively). However, to achieve a thorough formulation with an integrative conceptualisation of factors, the biopsychosocial model would be useful (Reuber, 2009), but is beyond the scope of this study. For example, the individual's history, environment, or personality, may provide detailed information about the predisposing, precipitating, and perpetuating factors associated with the experience of a PS event (Reuber, 2009).

Unexpectedly, considering that participants had been referred to cardiology, they did not report anxiety regarding a possible heart problem. This may be explained by the fact that participants had already been through numerous investigations and cardiology was perceived as another. What was apparent was that 'the brain or the head' played a large part in participants' anxieties. This may be related to a connection with PS and epilepsy or seizures. Arguably, participants may have been hypervigilant about the 'head', as the diagnosis was based on 'something' psychologically 'wrong with' the 'self' or the 'head'. Saliently, it is worth noting that neurology specialisations and the variety of diagnostic terms employed seem to dominate the condition of PS. Hence, it may be worth considering whether cardiology should play a larger role in identifying with the condition, although that may depend on the prevalence of patients within the specialisations. However, it might lead to less of an adverse association with the 'brain' among patients who refer through cardiology. What is more, some of the participants reported trauma, bereavement, dissociative experience, and psychosocial difficulties. These appear to be similar to the experiences of people with epilepsy as found in literature (Hansen, 2014, 'in preparation'). Future research may be able to address this possibility of homogeneity across the domains of cardiology and neurology.

It may now be useful to consider the psychosocial influences on individuals with PS. A wider understanding of the experience of PS may offer a more integrated health care approach (Gilbert, 1995). Themes identified in this study, are illustrated

in *Figure 2*. in order to provide a sense of the person in context. The illustration is based on the ecological systems theory (Bronfenbrenner, 1979), which has similarities to the biopsychosocial model (Engel, 1980). However, this model is less linear in its approach so may illustrate broader influences. Hence, a conceptualisation that includes multidirectional influences on individuals and a psychosocial 'zone of complexity' may be useful (Plesk & Greenhalgh, 2001).



Psychosocial information, advice, schools, communities, hospitals. - Psycho-education on anxiety, stress physiological effects, MUS

Systemic counselling- involve family discussion, support, curiosity, open dialogue

Peer Support, reduce isolation, gain confidence, normalise experiences, recreate self-identity

Promote social activities, CPN support & encourage to go out alone

Mindfulness, relaxation, meditation,

Morita, acceptance **Emotion-focused therapies, validate and make sense of emotions, express, talk about feelings**

Compassion-focused therapies

Health Services - Information at casualty/GP points of contact- helpful numbers, peers contacts, psycho-education communication re MUS, training, teaching staff

Figure 2. An illustration to conceptualise PS with multidirectional influences on the individual, incorporating the identified themes and descriptions from this study (adapted from Bronfenbrenner, 1979, 1994), incorporating interventions.

As illustrated in *Figure 2*, stigma may be reflected through media and society to the individual. In turn, the individual diagnosed with PS is coping with various experiences (which the themes represent) possibly due to an inexplicable illness, delegitimised by society (Ware, 1992). CFS was widely known to be stigmatised, especially at the stage prior to popularised acceptability (Kirmayer et al., 2004; Ware, 1992). Hence, with the apparent psychosocial factors present in PS, it may be useful to consider interventions that incorporate social milieu, in order to reduce stigma.

As previously discussed, influences of the Western mind-body ideology potentially contributes to the sense of a disconnected self. Equally, the historical over-medicalization of the female body, the notion of hysteria and role oppression, may have contributed to the prevalence of females diagnosed with PS, and the possible consequences of emotion suppression.

Importantly, health services may be a first point of contact for people with a PS event. Participants' accounts appeared to report being unhelpfully received at casualty services, or at GP's, on numerous occasions: '*I get ignored*' (Flo) or '*everybody is saying everything's fine, but I'm not fine*' (Debs). To explain this for example, it may be that in hospital settings the transition stage into the 'patient role' 'disappears' in the context of medically unexplained illnesses (Goffman, 1974, as cited in Young, 1989). In clinical environments, the patient role transition is a socially accepted role procedure, albeit unconsciously (Young, 1989). Hence, in PS a patient role may not occur and a further sense of displacement may take place

(Young, 1989). Further research is needed to explore the relationship between health services and people experiencing PS.

Equally in some of the participants' accounts, neighbours, family, or friends, did not understand their blackouts, which may have explained their sense of isolation. Family members of people with PS may themselves need support and information. Indeed, literature suggests that high levels of distress may be found in caregivers of people with epilepsy worldwide (Yusuf, Nuhu & Olisah, 2013). Considering that distress in people diagnosed with PS is reported to be equal to people with epilepsy (Karterud et al. 2009), it follows that the families of people with PS may also need support.

Thus, it can be seen that multidirectional influences may permeate back and forth, in dynamic interrelations, which fits with the 'complex adaptive systems' theory (Plesk & Greenhalgh, 2001, 2006). The 'complex adaptive system' supports the heterogeneity of influential factors in health care. The system highlights unpredictability, and an intuitive holistic application, in which to approach health care. This is contrasted with the need to categorise each symptom as a separate unit (Plesk & Greenhalgh, 2001). This approach may be useful in understanding the vast array of PS presentations, and more so accept the unclear boundaries of symptoms in PS as an illness.

4. Discussion

This IPA study explored the experience of people diagnosed with PS and the findings concur with literature in the field of NEAD or PNES (Brown et al. 2011, Reuber, 2009). The study highlights the adverse impact on people diagnosed with PS, with experiences such as psychological distress, anxiety, fear, dissociative experience, exhaustion, a lost sense of self, and possibly ensuing social stigma. A key issue appears to be the lack of an explanatory model to represent the experience of PS for patients. Critically, this may have clinical implications for recovery, such as poor adjustment and health outcomes, through a lack of understanding and accepting the diagnosis (LaChapelle et al. 2008).

The super-ordinate theme of 'Disconnection' appeared to be one of the key experiences of the participants. The theme related to the sense of a mind-body separation with possible roots in Western philosophy. It led to participants feeling a sense of alienation from their brain, which may be due to the lack of a way to represent PS as an illness. Equally, some participants described not going out, so it may be said that they felt disconnected from family or society, as well as from their past more confident self. The wider explanation may be related to the lack of illness representation resulting in 'ontological alienation', described as the sense of disconnection from the self and society, due to uncertainty of identity, or self-knowledge (Heidegger, 1962, Cameron & Leventhal, 2003). Philosophy describes this experience as a 'fallen' understanding of being in the world (Heidegger, 1962, Merleau-Ponty, 1962, respectively). Notably, 'fallen' appears to resonate with the experience of a possible dissociative collapse in PS.

Furthermore, it appears that a socially legitimate diagnosis is absent in PS, hence the transition period from symptoms to receiving a satisfactory diagnosis may not have occurred. To qualify this, further parallels may be drawn between the

'delegitimised' condition of CFS twenty years ago (Kleinman, 1992, as cited in Ware, 1992) and with PS today. CFS has become a more legitimate condition and socially accepted (Ware, 1992). One means of achieving a 'popular' legitimised condition for PS may be to use new terminology (Ware, 1992). Saliently, reducing negative terminology may lead to improved patient health outcomes (Wakefield, 2007). As well as finding new metaphors for use in health care to enable a more holistic terminology as suggested by Plesk & Greenhalgh (2001), new terminology may be needed to make PS understandable to patients.

A dissociative experience appears to be a core, 'socially visible', component of PS for participants. In support, as widely suggested in literature, dissociation appears to be a key factor in peoples' experience of PS (Brown et al. 2011; Jones et al. 2010; Bodde et al., 2009; Reuber, 2009). Hence, the author proposes the new diagnostic term of 'dissociative syncope' for use initially within cardiology speciality. The inherent difficulties in communicating the diagnosis of PS, or indeed NEAD or PNES, between clinicians and patients and their families, appears to be largely due to stigmatised terminology (Stone, 2013, DOH, 2011, Karterud et al., 2009; Ware, 1992). Thus, a more constructive term such as dissociative syncope, may create a more positive experience in communicating the diagnosis.

Importantly, dissociative syncope disengages from a 'psychogenic' label, which may contribute to, for example, participants thinking that PS is '*all in the head*' (Fiona) or that they are '*doing it on purpose*' (Sharon). Indeed, the value of a new diagnostic term may enable patients to inclusively engage with services, and reduce 'disappearance' from clinics once diagnosis has taken place (Karterud et al., 2009). Equally, it may benefit the formulation-driven approach, crucial in understanding individual complexity in PS, by encouraging patients to talk about their experiences in therapeutic intervention without fear of stigma. Furthermore, participants within this study highlight the lack of understanding about what the

diagnosis of PS actually means. As a consequence they appeared to be isolated from family, friends and the wider community due to having an inexplicable illness. To contextualise participants' concerns within wider socio-cultural influences, offers a more meaningful interpretation in this phenomenological analysis (Larkin, Watts, & Clifton, 2006). Hence, the socio-cultural environment, which defines diagnostic terminology, appears to have left people unable to identify with or accept their diagnosis, which as a result may impede their recovery (DOH, 2011, Garand et al. 2009, LaChapelle et al., 2008, Wakefield, 2007, Fitzpatrick & Cooper, 2006, Ware, 1992). Thus, 'dissociative syncope' may legitimise the condition and provide an acceptable diagnosis, reduce isolation, and hence engender a recovery process. Further research is imperative to examine terminology and its acceptability to patients and their families.

A dissociative experience was described in the subordinate themes of 'cul-de-sac' and 'three monkeys', from an emotional and physical dimension. There was an overall felt sense of a cul-de-sac with participants unable to find solutions, be understood, explain, or alleviate their condition. A result of a lack of illness representation with allusions to ontological alienation may be that people do not have 'frame of reference' in order to recover (Willet & Deegan, 2001). Indeed, reintegrating into society appears to be difficult for people with PS, especially as the majority of participants did not go outside their homes unaccompanied. People diagnosed with PS may be described as between role positions, in that they may not be a 'medical' patient, nor may they have an active role in society. Therefore, there may be a tangible feeling of suspension with their life '*on hold*' (Debs). Also, this may reduce the ability to reintegrate '*back to myself*' (Debs), or into society, which may relate to difficulties in adjustment to illness and role changes (Valente et al., 2009). Overall, a sense of threat, in PS as a condition may be present, due to

uncertainty in making sense of their illness' (Wisdom et al., 2008; Charmaz, 1983; Leventhal et al. 1984).

The participants' descriptions about seeing, hearing and speaking were illuminating. The accounts of '*can hear*' (Fiona, Maisie, and Flo) but '*not see*' or '*couldn't look*' (Fiona, Maisie, and Flo) may suggest a voluntary reflex, which concurs with current literature (Saal & Dijk, 2014). However, although this remains uncertain, the pattern was repeated across the majority of participants.

The theme of uncertainty appeared related to fear around the unpredictability of blackouts, and the '*felt*' unsafe environment in which they may occur. Critically, being unable to explain an illness to people may have contributed to the fear about blacking out in public. Hence, fear may be reduced for example, when a clear explanation of PS becomes available within the health care system.

The theme of battlefield appeared to be an ongoing fight with symptoms, and to make sense of what was happening with a blackout experience, or go outside. Fighting appeared to be exhausting, combined with a sense of ambivalence to fight or to give up: '*accept it, don't, do, and it's like you don't*' (Fiona). It appeared that participants had an ongoing struggle with PS, with little evidence of acceptance, or adjustment to living with the condition. This may be understandable with peoples' lack of a clear explanation of the phenomena of PS. Nevertheless, there was a felt, or intuitive sense, of resilience, strength, and determination within the participants' and their accounts.

The use of metaphor subscribed to an emotional depth in the experience of PS, and potentially offers participants a means of expression to validate their experiences, in society (Hollan, 2004). Equally, it is proposed that emotion language may transform self-identity through processes of emotion expression

(Salvatore & Venuleo, 2008). This indicates that employing interventions such as emotion-focused therapies may be useful (Greenberg, 2004).

Participants themselves provided ideas for what might help them: '*what can I do*' (Fiona) '*support groups*' (Debs), '*advice*', '*a nurse to talk to*' (Debs), or '*explain to me, instead of reading a booklet*' (Fiona). Subsequently, psycho-education, or peer support may be helpful as interventions with this patient group. Peer support is widely acknowledged to be efficacious with for example, general health care, anxiety and depression (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2010; Repper and Carter, 2010; Dennis, 2003). Further research may examine whether peer support is helpful for people with PS.

Overall, the experience of blackouts, as identified in these themes, appears to have an adverse physical, emotional, and social impact on the participants. As is commonly reported in MUS literature, the themes in PS appear to overlap, and be interrelated. This is illustrated in *Figure 3*, which extends a mapping of MUS for PS (Marchetti et al. 2008).

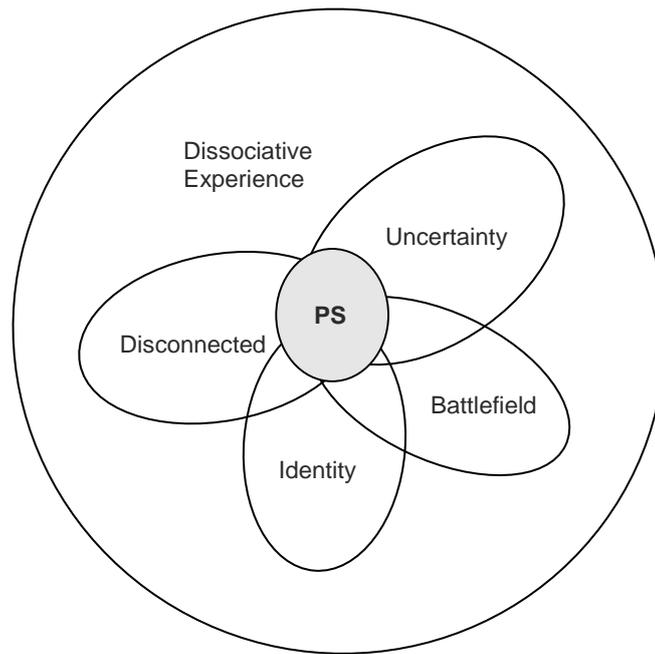


Figure 3. An illustration of the possible inter-relational properties of the super-ordinate themes identified in this study.

Overall, it appeared that dissociative experience may have an overwhelming effect on participants' emotional and mental wellbeing. The sense of a loss of self-identity, as described by participants may for example, correspond with a disconnected sense of self (Wisdom et al. 2008). Equally, the experience of constantly fighting may relate to the uncertainty in how to represent the possible dissociative experience. Hence, the interrelations appear to be extensive and complex, which concurs with the need to incorporate a 'complex adaptive systems' approach into healthcare practice (Plesk & Greenhalgh, 2001). Further research is needed to enable a more holistic approach in which to understand the experience of PS.

Lastly, people regardless of the condition they are experiencing, need a language in which to explain and understand their illness. PS appears not to have a language in which people may exist in the world. Foucault (1984) challenges us to consider that the 'anxiety of our era' is related to space; private, public, and cultural. To elucidate this concept within PS, consider a theatre stage, where fainting is

acceptable as dramatic emotion, a socially understood expression. A PS diagnosis can be said to be partitioned by the curtains of culture; what is legitimately accepted. Understanding the experience of PS needs to be established in context as it dependent upon the 'space', or era in which it arises as a diagnosis (Foucault, 1984). It may be that PS can be understood more easily through a change of terminology (Larkin, Watts & Clifton, 2006). Hence, new terminology, such as dissociative syncope may increase acceptance, and understanding for the patient. In turn, for the individual this may enable a sense of a more integrated self, supported by society.

5. Conclusion

The insight into people's experiences of PS highlighted a daily struggle to reconstruct a sense of self and to make sense of a variety of sensations, and symptoms around collapsing. This sense of struggle appeared to infuse into peoples' daily activities and social environments, it was felt that in whatever direction people turned there was an impasse, with a pervasive uncertainty. This appeared to result from a lack of a clear understanding of their diagnosis. In conjunction with these factors was a deep need to return to living, to meaningful roles in society, and be understood by family, health services, and society in general. The inherent complex influences on PS appears to have gathered centuries of stigma-related perspectives. Such perspectives may adversely affect people who experience unexplained symptoms to this day. It appears imperative to individual, and social, health and well-being that a more holistic perspective is engendered throughout the healthcare system, as suggested by Plesk and Greenhalgh, (2001). For individual health and wellbeing an explanatory model of PS is needed to establish better understanding as a diagnosis. A way to generate a socially legitimate and inclusive perspective of PS may firstly, and simply, be by changing the diagnostic term of PS to dissociative syncope. Subsequently, as

widely understood, understanding a diagnosis may empower people and their families in the process of recovery.

6. Clinical Implications

The 'complex adaptive system' (Plesk & Greenhalgh, 2001) with its understanding of multidirectional influences, and intuitive holistic approaches may be useful as a framework to integrate into health care practice for PS. For better health outcomes, peoples' acceptance of their condition through improved understanding of PS, may lead to better adjustment and coping (Valente et al. 2009; LaChapelle et al., 2008; Moss-Morris, 2002; Leventhal et al., 1984). Parallel to this needs to be provision of a clear diagnostic process leading to clear interventions.

Hence, the multiple dimensions that may present in the experience of PS, should be brought into awareness in diagnostic pathways for healthcare. For example, four out of six participants had experienced bereavement, or loss of social roles via unemployment. Hence, it may be useful to be aware of possible factors within assessment. Further dimensions may include for example, anxiety, fatigue, depression, or psychosocial problems associated with role change such as isolation. A possible way forward may be assessment that includes a phenomenological perspective. For example, a 'phenomenological interviewer', with intuitive awareness skills of the personal and contextual factors, which may be operating in a patient's life (Parnas, Sass & Zahavi, 2012). This would evolve around person-centred therapy, with self-reflection, and the 'interviewer' exploring a different worldview, or 'being in the world' (Parnas, et al. 2012). A phenomenology approach would be balanced with a systematic assessment and in the process may add to a more comprehensive holistic diagnosis, in PS.

Importantly, the participants themselves provided ways to progress toward interventions that may empower them. This included more information, a clear diagnosis with time to ask further questions, so that they can make sense of their

experience, and peer support. Peer support, widely regarded as efficacious, is a socially inclusive activity that may help to increase mood and adaptive coping skills (Repper and Carter, 2010; Valente et al., 2009; LaChapelle et al. 2008), and reduce isolation for this patient group. Pertinently for people diagnosed with PS, peer support may provide or recreate a strong sense of self-identity (Charmaz, 1983).

Considering the role of psychosocial factors in better adjustment and coping with illness, it may be useful to incorporate psychosocial interventions into healthcare for people with PS (Lukens & McFarlane, 2004). A perceived stigma due to a sense of difference and isolation was described across participants' accounts. So interventions that target social barriers and incorporate mental and emotional health could be targeted at communities, or schools, in order to reduce stigma (Lukens & McFarlane, 2004; Plesk & Greenhalgh, 2001). Equally, key information at the patients' critical point of contact, with hospitals, or GP surgeries, may be useful.

The lack of a coherent representation, which was a critical feature in accounts of the experience of PS, may have led to poor coping and increased anxiety (Valente et al., 2009; Hagger & Orbel, 2003). Psychoeducation may prove helpful to patients, caregivers, and clinicians, in managing the experience of PS. Information may provide a better understanding of PS, which may help to alleviate peoples' sense of a deconstructed self.

Mind-body therapies have been introduced into Western healthcare in patient groups, such as epilepsy, so may prove beneficial for patients with PS (Chan, Sze, Cheung, Lam, & Shi, 2009; Wahbeh, Elsas, & Oken, 2008). Therapies such as Morita therapy, which involves mindfulness, relaxation or meditation, may alleviate anxiety or stress, in patients with PS (Morita, 1998). Relevantly, it is based on

acceptance of feelings of distress, so may lessen peoples' sense of 'fighting', and also reduce avoidant coping styles (Hoffman, 2008). Equally, it may help to recreate a holistic sense of self (Chan et al. 2009).

In addition, it may be helpful for patients with PS to be offered 'Emotion-Focused Therapy', or 'Compassion-Focused Therapy', in order to validate experiences and process difficult emotions (Gilbert, 2009; Greenberg, 2004). Importantly, the extent of trauma as a contributory factor across presentations of PS could also be targeted with compassion-focused therapy (Greenberg, 2004; Paivio & Nieuwenhuis, 2001). Relevantly, emotion processing has been found to increase adjustment to illness and reduce numerous appointments to services (Stanton et al., 2000 as cited in Greenberg, 2004). Equally useful may be a strengths-based narrative therapy, where patient recovery is focused on possibilities and self-strengths, which may decrease isolation and improve confidence (Wisdom et al. 2008).

Importantly, eight out of nine invited Asian British patients did not participate in the study. The clinical implications for this may be for example, that this population is underrepresented in receiving health care for PS. Also, half of the Asian British potential participants were males. So further research may establish the prevalence and needs of males with PS, in the Asian British population. It may be helpful to incorporate culturally different interventions, such as elements of Morita Therapy (Spitzer, Barnow, Freyberger, & Grabe, 2006), and to explore what interventions may be acceptable to minority populations.

Finally, cognitive behaviour therapies have shown to be beneficial in recovery towards self-acceptance and recovery from chronic stigma-related conditions (Corrigan & Knudsen, 2005). Conclusively, these interventions may prove

beneficial to people and are in line with the current strategies for improving mental healthcare, holistically, in the population (DoH, 2011)

7. Limitations

Although rich data was collected within this study, with IPA research it is not possible to generalise to the population (Brocki & Wearden, 2006). The time of diagnosis was varied across participants from a range of one week, to two to five years. So, for example, newly diagnosed participants may have reported different accounts of anxiety, or other symptoms, compared to people with a more chronic experience of PS anxiety (Charmaz, 1983). Also, for example, levels of depression may be different at various stages of diagnosis (Charmaz, 1983). Equally, varying personal, psychosocial or environmental factors may have influenced participants' accounts. Equally, there was heterogeneity across in the age range, 18-56 years old, which may reflect different lifestyles or beliefs at varying stages of life (Erikson, 1959).

Furthermore, all of the participants were recruited from the same clinic, so their experience of diagnosis or interaction with care teams may have been homogenous. Also, participants were recruited from the same city, experiences may differ elsewhere in the United Kingdom. Further research could establish whether this is the case.

Further limitations are that participants were all females, hence information about male experiences in PS and related needs could not be established. Equally the researcher's female gender, age, and professional background may all have impacted on the participant's extent of disclosure and description of PS. Similarly, the choice of interview questions may have influenced participant's responses. Additionally, it is possible for example, that projection may have occurred in the interviews where descriptions were felt more strongly by the researcher when

trauma or distress were described, resulting in amplified interpretation of phenomena (Rizq, 2012).

Additionally, there may have been a self-selecting sample bias, with possibly more evidence of depression or anxiety present in those who did not participate (Fischer & Hood, 2011). In support, twenty six people chose not to participate in the study, some after expressing interest, which could indicate higher anxiety levels in those who declined. Equally, this may have been due to participants' being unable to go outside the home.

Lastly, the validity of the IPA collection and data analysis may have inherent biases due to the researcher's interpretation. The researcher attempted to reduce subjective interpretation through ongoing reflection and discussion of emerging themes with independent researchers. Another means would have been to validate the study by gaining participants thoughts on themes to increase the credibility of the study. Findings were unable to reflect or add to cultural information, due to a lack of minority groups participating.

8. Future Directions

Clearly, more research is needed in order to understand peoples' experiences of PS within cardiology speciality. This would add to literature, which has mostly overlooked this area of PS, and provide information to target interventions for patients diagnosed, via this route. Further qualitative research is needed to extend knowledge about people's experience of PS, so that a holistic approach may be incorporated into interventions.

Males diagnosed with PS needs further investigation since it is uncertain what the experiences and needs are of males in this population group. Equally research may establish whether older people diagnosed with PS are overlooked, due to the

younger adults reported as presenting more frequently in literature (Alsaadli & Marquez, 2005).

As this study was mainly conducted with White British participants, research into the experience and needs of ethnic minorities needs to be taken onto account. This may be salient to stigma related differences between cultures, or how different communities may represent PS as an illness (Hollan, 2004; Senft, 1998). This might ascertain for example, whether culture influences peoples' responses to illness, which could explain the fewer respondents in this study from the Asian British population. Equally, to explore whether Western cultures have more prevalence in people experiencing PS compared to the more holistically oriented Eastern hemisphere may be useful.

Importantly, families of participants appeared to possess valuable experience to share in their accounts. Potentially their experience of PS may be useful to improve healthcare in people with PS from a holistic perspective, and provide support for their partners and families.

The idea of including phenomenology approaches in assessment or interventions may be useful, and needs further exploration. Equally beneficial may be exploring the effectiveness of metaphors and idioms of distress in order to interpret emotion at depth within emotion-focused therapies.

This study identified key experiences from people with PS, via cardiology, as opposed to PNES or NEAD pathways. It is possible that there may be similarities between patient experiences of for example, PS and NEAD and PNES. Therefore, investigation into clinical implications of this for the patient needs further development. For example, to establish whether diagnosing people using one term across the PS spectrum, improves understanding and acceptance of this currently medically unexplainable illness.

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Part Three

Appendices

APPENDIX A - GUIDE FOR AUTHORS – *International Journal of Cardiology*

Introduction

The International Journal of Cardiology is a global journal of cardiology, cardio-metabolic and vascular sciences. Articles reporting clinical observations and interventions, experimental studies and theoretical concepts are all welcome provided they are of major scientific importance and clinical relevance.

The journal covers all aspects of cardiology from genes to populations. The journal commission's high quality review articles from distinguished authors; unsolicited reviews will also be considered and will be subject to peer review. Letters to the editor are welcome. Case reports can only be considered if formatted as a letter. Submission of a manuscript to this journal gives the publisher the right to publish that paper if it is accepted. Manuscripts may be edited to improve clarity and expression

1. ORIGINAL ARTICLES

Original Articles should report original research not previously published or being considered for publication elsewhere, meeting high standards of scientific integrity. There is no maximum word count. The standard layout is given below. Layout Of Original Articles

Divide the manuscript into the following sections: Title page, Structured Abstract, Key words (3-6), Introduction, Methods, Results, Discussion, Acknowledgments, References. The editors will consider the use of other sections if more suitable for certain manuscripts. Type double-spaced. The Title Page should include:

1. The title (not to exceed 25 words)
 2. The full list of authors and for each author a numbered footnote. The footnote should state the author's academic affiliation and the following statement of authorship: "This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation". Any author unable to make this statement must instead state their specific contribution to the manuscript.
 3. Corresponding author and contact details
 4. Acknowledgement of grant support
 5. Any potential conflicts of interest, including related consultancies, shareholdings and funding grants
 6. A list of up to 6 keywords
- The Next Page Should Include:

A Structured Abstract, of no more than 250 words. As this may be the only part of the article read by some readers it must include sufficient detail for an adequate summary of the whole manuscript. The preferred subheadings are Background,

Methods, Results and Conclusions, although a merged Methods and Results subheading is also permitted if this permits more economical expression. The Next Page should commence the main article subdivided into the following sections: The Introduction should be brief and set out why the study has been performed along with a review of relevant previous work only where essential.

The Methods should be sufficiently detailed so that readers and reviewers can understand precisely what has been done. Standard methods can be referenced. Manuscripts reporting data obtained from research conducted in human subjects must include a statement of assurance in the Methods section of the manuscript that (1) informed consent was obtained from each patient and (2) the study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in a priori approval by the institution's human research committee. Manuscripts reporting experiments using animals must include a statement giving assurance that all animals received humane care and that study protocols comply with the institution's guidelines

The Discussion should directly relate to the study being reported rather than a general review of the topic. A Study limitations subsection must be included and should disclose any reasons the findings may not be applicable more broadly. Conclusions should be limited to a brief summary and the implications of the data presented. References Discoverability of research and high quality peer review are ensured by online links to the sources cited. In order to allow us to create links within ScienceDirect and to abstracting and indexing services, such as Scopus, CrossRef or PubMed, please ensure that data provided in the references are correct. Please note that incorrect surnames, journal/book titles, publication year and pagination may prevent the link creation. When copying references, please be careful as they may already contain an error.

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume and issue/book chapter and the pagination must be present.

The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that incorrect or missing data will be highlighted at proof stage for the author to correct. The reference style used by this journal is Vancouver Numbered. If you do wish to format the references yourself they should be arranged according to the following examples Examples: [1]

De Soyza N, Thenabadu PN, Murphy ML, Kane JJ, Doherty JE. Ventricular arrhythmia before and after aortocoronary bypass surgery. *Int J Cardiol* 1981;

1:123-130. [2] Akutsu T. Artificial heart:total replacement and partial support. Amsterdam: Elsevier/North-Holland, 1975. [3] Goldman RH. Digitalis toxicity. In: Bristow MR, editors. Drug-induced heart disease. Amsterdam: Elsevier/North- Holland, 1980:217-40.

Please note that all authors should be listed when Tables should be typed with double spacing and each should be on a separate sheet. They should be numbered consecutively with Arabic numerals, and contain only horizontal lines. Provide a short descriptive heading above each table with footnotes and/or explanations underneath. Figures should ideally be submitted in high-resolution TIF format, or alternatively in GIF, JPEG/JPG, or EPS format.

The figures should be placed in separate files, named only with the figure numbers (e.g. "Figure1.tif".) The cost of colour figures will be paid by the author.

2. REVIEW ARTICLES Reviews of recent developments are welcome, and will undergo peer review. Reviews should have an unstructured abstract of up to 250 words. Authors are encouraged to use section headings for ease of reading. They do not have an introduction, methods, results or discussion sections. Type double-spaced. For instructions on references and figures please refer to the section on original manuscripts.

Process of Submission

The International Journal of Cardiology is a fully electronic journal. All manuscripts MUST be submitted via the Internet to the following Elsevier website:

<http://www.ees.elsevier.com/ijc/>. DO NOT email the manuscript to the journal or editors. Author Agreement Form. All authors and contributors must submit a form stating their role in the article. This form is available to download directly from the last screen in the submission process. The International Journal of Cardiology requires all authors to sign this form. Articles will not be published until these are received.

Changes to Authorship This policy concerns the addition, deletion, or rearrangement of author names in the authorship of accepted manuscripts: Before the accepted manuscript is published in an online issue: Requests to add or remove an author, or to rearrange the author names, must be sent to the Journal Manager from the corresponding author of the accepted manuscript and must include: (a) the reason the name should be added or removed, or the author names rearranged and (b) written AUTHOR INFORMATION PACK 10 Dec 2014 www.elsevier.com/locate/ijcard 7 signed confirmation from ALL authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed. Requests that are not sent by the

corresponding author will be forwarded by the Journal Manager to the corresponding author, who must follow the procedure as described above.

Note that: (1) Journal Managers will inform the Journal Editors of any such requests and (2) publication of the accepted manuscript in an online issue is suspended until authorship has been agreed. After the accepted manuscript is published in an online issue: Any requests to add, delete, or rearrange author names in an article already published online must follow the same policies as noted above. If accepted, the change will be noted by the publication of a corrigendum.

Preparation of supplementary data International Journal of Cardiology publishes electronic supplementary material to enhance your scientific research presentation, increase transparency, and support scientific integrity. It is required that raw data for figures should be presented, and the author is invited voluntarily to publish in full the detailed dataset of the study. Supplementary files may also include supporting applications, movies, animation sequences, high-resolution images, background datasets, sound clips or other helpful items. Supplementary files supplied will be published online alongside the electronic version of your article in Elsevier web products, including ScienceDirect: <http://www.sciencedirect.com>.

PREPARATION

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2.), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line. *Introduction* State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section. *Appendices*

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

APPENDIX B – Data Extraction Tool

Title of Study	
Author/s Publication Date Country	
Study Aims	Rationale
Design Statistical tests	
Characteristics of sample	Number Age Gender Socio-demographics
Outcome Measures Interviews	Questionnaires Profession of person taking assessment
Key Findings	Results Conclusions
Main limitations identified in study	
Quality Score	
Specialisation Context of study	Neurology Psychiatry Psychology Epilepsy Other

APPENDIX C - Quality Assessment Tool

Adapted from *STROBE* Vandembroucke et al. (2007).

Criteria		Response			
		Yes 2	No 0	Partial 1	Not clear 0
I. Abstract	Does it provide a balanced and structured summary of the design, methods, results, and conclusions?				
II. Introduction Background and Rationale	Does it explain the scientific background and rationale for the investigation being reported?				
Aims Objectives	State specific objectives, pre-specified hypotheses, if applicable, and Design?				
Conceptual	Are the key concepts of the study well defined?				
Application	Is there a rationale transferable to patient/ clinical environments?				
I. Methods					
Setting	Are the location, dates, recruitment, exposure, follow-up and data collection described?				
Design	Key elements of the design clearly presented early in the study?				
	Provide adequate description of the measures used in				

	assessment? (e.g. questionnaires or interview schedule or topics)				
	Do measures have clear validity or standardised? Comparability of assessment method if more than one group?				
	Are the reports, archives, or observations, relevant to the study objective?				
	Is there an acceptable response rate? (60% or above)				
Participants	Are participant characteristics clearly described? (e.g. age, sex, number, social, diagnosis)				
	Inclusion and exclusion criteria?				
	Is missing data accounted for?				
	Is rationale given for choice of cases and controls?				
	Was the sample representative of the entire population from which they were recruited?				
II. Results	Are the key findings summarised in relation to the study aims?				
	Are researcher characteristics taken into account on when describing the results?				
	Have the researchers controlled for group (case vs controls) differences?				
	Were the statistical tests appropriate for the main outcome?				
	Provide confounder-adjusted estimates and their precision, if				

	applicable (e.g. 95% Confidence Interval).				
III. Discussion	Are key results summarised with reference to study objectives?				
Limitations	Discuss limitations of the study, accounting for sources of bias or imprecision?				
Generalizability	Does the study discuss the generalizability of findings?				
Interpretation	Is an overall cautious account of interpretation provided, considering limitations, results from other studies, multiplicity of analysis?				
Research	Are avenues for future research highlighted?				
	Total				

Criteria	Awad & Softić, (2011)	D'Alessio et al. (2006)	Marchetti et al. (2008)	van Merode et al. (2004)	Mitchell et al. (2012)	Mökleby et al. (2002)	Moore & Baker (1997)	Myers et al. (2012)	Pročena et al. (2011)	Tojek et al. (2000)	Turner et al. (2011)	Total	Max Score	
Comparability of assessment	2	2	2	2	2	1	NA	NA	1	2	2	16	18	
Assessment tools relevant	1	1	2	2	1	2	1	2	2	2	2	18	22	
Response rate acceptable	NA	NA	NA	2	2	NA	NA	NA	2	2	NA	8	8	
Participant characteristics	0	1	1	1	1	2	2	1	1	2	1	13	12	
Inclusion/exclusion criteria	2	1	1	1	2	2	0	2	1	1	2	15	22	
Missing data	0	0	0	0	2	0	0	0	0	0	0	2	22	
Choice of cases/controls	1	1	1	2	2	2	1	2	1	2	2	17	22	
Representative sample	1	1	1	2	2	1	2	1	1	1	1	14	22	
Results														
Clear summary in relation to	2	2	1	2	2	2	1	2	2	1	2	19	22	
Researcher influence	0	1	2	2	0	0	0	0	1	1	0	7	22	
Control for case vs group	0	0	0	1	2	2	NA	NA	2	2	1	10	18	
Appropriate test outcomes	2	2	0	2	2	2	1	2	2	2	2	17	22	
Confidence intervals	0	0	0	0	2	0	NA	0	0	2	0	4	20	

Criteria	Awad & Sofrić, (2011)	D'Alessio et al. (2006)	Marchetti et al. (2008)	van Merode et al. (2004)	Mitchell et al. (2012)	Mökleby et al. (2002)	Moore & Baker (1997)	Myers et al. (2012)	Pročena et al. (2011)	Tojek et al. (2000)	Turner et al. (2011)	Total	Max Score	
Discussion														
Key summary	2	1	1	1	2	2	1	2	2	2	1	17	22	
Limitations	0	0	0	1	2	0	1	1	2	2	1	10	22	
Generalizability	0	2	0	1	2	2	1	0	1	1	2	12	22	
Interpretation	1	2	1	2	2	1	2	2	2	2	2	19	22	
Future research	0	1	0	1	2	1	1	2	1	2	1	12	22	
Total	25/53	32/53	24/53	38/54	46/54	38/53	24/50	33/51	37/54	43/54	38/53			
Percentage	45%	60%	45%	70%	85%	71%	48%	64%		68%	79%	71%	M =64%	

APPENDIX E - Semi-Structured Interview Schedule

Semi-Structured Interview Schedule

Interview length 60 minutes

Date:

Time:

Introduction: Thank you for agreeing to take part in an interview about your experience of blackouts. We have up to 60 minutes, if you need a break during the interview, please say, or if you need to stop the interview for any reason we shall do so. Also, if you wish to finish early, please tell me.

I would like to remind you that this interview will be confidential and will remain anonymous and records of the interview will be kept without your name on them. As we spoke about earlier, everything is confidential unless there is reason for risk to your safety or to someone else, in which case, I will discuss this with you first, and then need to inform the appropriate person, such as your G.P.

The interview, as we mentioned, is recorded for the purpose of getting an accurate account of your opinions and responses, and to help me to interpret the data of this study.

During the interview I hope to discuss with you for example, your experience of blackouts, how they affect your life, what you feel you can do about them, what has helped you, what does having a diagnosis mean and so on.

If you have any questions during the interview, please ask. Or, do you have any questions now before we start?

General opening questions

- What brought you to the blackout clinic at this point?

Topic 1¹⁶ – The symptoms and how they are interpreted

- What are the symptoms of your blackouts? How often do you experience them?
- How do you cope with blackouts - or what helps to lessen the symptoms or feelings around them? Can you describe what makes blackouts worse?
- Have the symptoms changed over time – in what way? Why do you think this is?

¹⁶ All of the questions are examples of intended questions but the course of the discussion is dependent on and will be led by the responses from the participant

Topic 2 – Duration of the condition

- How long have you had blackouts?
 - How long do you expect that you will continue to have blackouts?
 - Why do you think that blackouts will last that long? -
-

Topic 3- Perception of the emotional, physical, and social effect of the blackouts

- How does having blackouts affect your daily life?
 - How do they affect your social life or your physical health?
 - How much do the blackouts affect you emotionally? – do they make you angry, scared, upset or depressed?
 - Can you describe your overall experience of living with blackouts?
-

Topic 4- Perception of locus of control

- How much control do you feel that you have over your blackouts?
 - What do you think affects your blackouts?
 - What do you feel that you can do about the blackouts?
-

Topic 5 – Perceived Cause

- What do you think may have caused or contributed to your blackouts?
 - Have you had any experiences that you think may have contributed to blackouts?
-

Topic 6- The meaning of a having a psychogenic diagnosis

- Can you describe what does having a diagnosis of psychogenic syncope mean to you?
- What are your feelings about having a non-medical diagnosis?
- How does it affect your perception of blackouts?
- How well do you feel that you understand your blackouts?
- How much do you think that your treatment helps/is going to help your syncope?

General closing questions:

- Is there anything else that you would like to say about your experience of blackouts?
 - Is there anything else that you would like to say about anything that we have talked about?
-

Thank you for taking part in this interview. How do you feel? Do you have any questions about the interview or anything else? I will contact you, if you wish, about the findings of this interview to ask your opinion on the interpretation of this interview. If you need to contact me again about the interview, you have my contact details. Thank you.

APPENDIX F- Ethical Approval Documentation

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APPENDIX G - Participant Information Sheet

Participant information sheet

We would like to invite you to take part in our research study. Before you decide to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and feel free to discuss it with friends or relatives if you wish. If you need further information, please don't hesitate to ask the researcher.

Who is organising this research?

This research is being carried out as part of a doctoral qualification in clinical psychology at the University of Hull. The study has been assessed by the [name of ethics committee here] NHS Ethics committee and given a favourable opinion. This means that the study has been checked to make sure it will be conducted appropriately and ethically.

What is the purpose of the study?

This study looks at the experience of people with blackouts with no known medical explanation. Blackouts, or 'psychogenic syncope' a term that you may have seen in the booklet that you have been given by the blackout nurse, is largely an under-researched area. So not a lot is known about what patients think or feel about having it. This study is aimed at better understanding people's experience of blackouts, how it affects well-being and life in general.

Why have I been invited?

As a patient with experience of blackouts you have been asked to share your experience of living with blackouts. All patients who have a diagnosis of blackouts and who are under the care of the blackout clinic are being invited to take part. We hope to have eight participants in this study.

Do I have to take part?

It is up to you to decide, participation is voluntary. You do not have to take part and if you do not take part your ongoing treatment, or contact with the clinic, will not be affected. The study described in this information sheet details what the study will involve. You will also have a chance to speak with the researcher directly, should you have any questions or concerns.

What will happen to me if I take part?

- You will be interviewed by the researcher
- The interview will take place at a venue of your choice at your convenience: the hospital where you attend the blackout clinic, or at your home.
- You will be asked to sign a consent form to show you have agreed to take part and that you have read and understood this information sheet.
- The researcher will ask for a contact person from you before the interview, if the interview is at your home, in case you feel upset or unwell.
- You will then be interviewed, which involves the researcher asking questions where there are no right or wrong answers. The researcher is interested in hearing your thoughts and feelings in an informal manner. The interview will be

audio-recorded anonymously in confidence, typed up afterwards, and destroyed when the study is finished.

- The interview will last for approximately 60 minutes, and be about your experiences of blackouts. The length of time is dependent on how you feel during the interview. The interview will be stopped or shortened if you feel tired or unwell, and proceed only if you feel able.
- You will only be asked to attend this one interview session.
- When the researcher has typed up the interview, they will look at what you have said to gain an understanding of your experiences. If you wish to, you may be sent a summary of the information from the interviews to gain your views on the researcher's interpretation, and your comments will be welcomed.
- Personal information such as names will not be taken at any time and anonymous recordings of the interviews will be securely stored and only accessed by the researcher or research supervisor. Transcripts from the interview, which would be confidential and anonymous, may be read by members of a clinical discussion group who will be commenting on themes that arise from the data.

What happens if I don't want to carry on with the study?

You are free to withdraw from the study, up to the point of transcription, at any time, without giving a reason, and the information that you gave will be destroyed. If you withdraw after the typing up of your information has finished, your information will be kept for the study because your specific information cannot be identified at this stage.

What are the disadvantages of taking part?

You may feel tired during the interview, if this occurs you can stop the interview and rest, or do whatever helps you. The interview may then continue if you feel ready to do so. If you do feel unwell by talking about your experience of blackouts, the researcher can get in touch with the contact person that you have chosen. The researcher may request a contact number from you for your next of kin, friend, or your G.P. in case of a problem or emergency. Or, the researcher can talk with you about stress relief or anxiety, and offer areas of possible referral and support for example, psychological services or your G.P.

If you have a blackout during the interview, the researcher would have asked you prior to interview what usually happens, and who to contact if your next of kin is not present, and how the researcher may help you, or not. If you feel well enough, you may choose to continue, or postpone the interview as you wish, or you can withdraw from taking part in the study altogether. If your next of kin is present, they will be responsible for your care if you have a blackout at your home. The blackout clinic will be informed within 48 hours that a blackout occurred, with your consent. If you experience a blackout, slip, or injure yourself at the clinic during the interview; the blackout nurse will be informed immediately, as necessary. These procedures will be discussed with you before the study in case you have questions.

What are the benefits of taking part?

We cannot say that the study will help you but the information that we get from the study may help improve the treatment of others with blackouts. It may also be helpful to have an opportunity to speak with someone about your experiences of blackouts.

Will my part in the study be kept confidential?

Yes, your name will be anonymised throughout the study, and your part in the study will be kept confidential. We will follow legal and ethical practice on all the information about you.

The only time that confidentiality would be broken is if you were to tell the researcher anything that may be a risk to you or anyone else's safety. The researcher will discuss the procedure for this with you first.

What happens to the findings of the study?

The study will be written up and submitted as part of a doctoral qualification. The final write up may also be published in an academic journal where others will be able to read the findings. Personal quotes given in the interview may be used to give readers an idea of participant's views; however, there will be no details used that would mean individual participants could be identified. So your view would remain entirely confidential and anonymous throughout, and at the end of the study. At the end of the study, you will receive a summary paper of the findings, if you wish to do so.

Further information and contact details

More detailed information about this study can be obtained directly from the researcher using the details below. If you are unhappy with the study you should contact myself as the main researcher and my details are provided below. I am supervised by Dr. Dorothy Frizelle.

Contact details of main researcher: Synn Hansen

Email: s.hansen@2004.hull.ac.uk

Address:

**Department of Psychological Health and Wellbeing
University of Hull
Hertford Building
Cottingham Road
Hull
HU6 7RX**

APPENDIX H - Participant Consent Form

Participant Identification Number:

Consent Form

Title of the Project: What are the experiences of people with psychogenic syncope?

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 01/11/2013 (version 1—01/11/2013) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the interview will be audio recorded and direct quotes may be used in subsequent publications but that I will never be identified from the quotes.

4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the research supervisor from The Department of Psychological Health and Wellbeing at The University of Hull, where it is relevant to my taking part in this research. I give permission for this individual to have access to my records.

5. I agree to take part in the above study

Name of participant Date Signature

Name of researcher Date Signature

APPENDIX I - Demographic Questions

DEMOGRAPHIC INFORMATION PRE-INTERVIEW

Please answer the following questions as best you can and ask if you need any help. Thank you for your time.

Date / /

Participant Number

Pseudonym ID.

1. AGE IN YEARS
2. GENDER MALE/FEMALE.....
3. TIME SINCE DIAGNOSIS.....
4. WHAT IS YOUR ETHNIC GROUP? Please tick and describe.
 - White British
 - Other White background
.....
 - Mixed/Multiple Ethnic Groups
.....
 - Asian/Asian British
.....
 - Black/African /Caribbean background, please describe
.....

Thank you!

APPENDIX J – HADS Questionnaire

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APPENDIX K – Worked Example of IPA

Initial comments, themes emerging

Maisie: I'm 18 and they told my dad we think she's going to be 18, then she's going to have 'em, but I started just having them sort of this year and...

R*. So this, this year.

Maisie : Yeah.

R. So you haven't had them up until this year?

Maisie: I had, um, I did have, the first, the very first one I had one was me daughter, she's 23, I was in town with my friend and we were just walking and then, um, all of a sudden I just fell and I'd collapsed and then they called an ambulance. And I didn't understand what it was, you know, but I felt dizzy and all that.

R. And so what happens when you get the blackout?

Maisie: Well what happens is I look drugged up and I mean I've, I've never smoked in my life or drank or had drugs but, I remember they got me up and I still felt like whoa I'm going to fall again, you know.

R, Yeah. What were you thinking when this was all happening to you?

Maisie: Um, just nothing, empty minded.

R. Yeah, yeah.

Maisie: Confused.

R. Yeah, confused..

Being all confused and not.....

R. What were you confused about, what....?

Maisie: Where am I or -

R. Yeah... or..

Maisie:- what's happening and...But then when I came around, um, when I had it on Monday, um, this Monday again town, um, I, I, when I came round a bit I'm like oh, I remember going to a lady, I remember actually going upstairs in the cafe and having cheese on toast –

R. Yeah

R* researcher

Grief related just after dad dies? Context

No warning?

Suddenness

Collapsed

Casualty-anxiety related?

Drugged up – fatigue? Other's description?

Going to fall- Warning,

Empty minded, accept

Confused Dizzy

Disoriented

Vague?

Animated Enthusiasm

In town-again-, social.. *happy expression*

Maisie:- and a cup of tea, and I thought I'm going to blackout, I'm going to blackout. That's all was in my head I were like, I were like that, you know, and then next thing, um, I went and sat on these chairs and, you know, a lot of people say Maisie are you okay, are you okay, because everybody knows me in town and they're like, you know, you okay? Because I know I'm going to blackout, I can't see properly. And, um, I just felt like I wanted to sleep as well and, um, so then I went into [shop] and next thing I remember going to this English lady. She said 'hi' to me, she worked there, I went 'Oh hiya', and she were like 'hiya', you know'.

I'm going to-
not sudden

contradiction

All in head,
make it up –
not real
Reassure, town
again, social..
happy beaming

'Knows'

'Can't see'

Tired 'drugged'
keen to recall
event, need for

Sharon: “.because I think oh, people think I'm doing it on purpose, and that I'm sure that is what is in back of my mind, no way I, I'm not doing it on purpose, I'd love not to do it. I'd love to have my own life back. So now, I pretend it hadn't happened sort of thing.

R. Okay, after a blackout?

Sharon: Er, yeah.

R. Yeah.

Sharon: And I just, er, let things go. But I kept thinking, I'd just try and put it down to something, 'you're alright', er, because it's a way I can cope.

R. So...

Sharon: I don't think about it so much, because if I'm trying to think, it's no good.

R. No good...

Sharon: I can't do it because, um, I get, I don't know, I just get a horrible feeling and that like ah.

R. So can you describe that- pretending a bit more, what do you...?

Sharon: I just don't, if it has, er, what do you mean by the pretend to?

R. Yeah, you said you pretend it hasn't happened...

Sharon: Yes, I just don't like to think it's happened.

'My fault, no
medical
explanation,
friends, street -
stigma Loss
old identity-
Other's words?
Lost job
context?–social
role, loss

Positive self
talk

No good –
unhelpful
coping

I can't, lack of
control.
Horrible? –later
described
scared, anxious

Defensive?

Avoidant
Coping

R. And you said not meant to have them, you said, what did you mean by not meant to?

Fiona: Er, well I don't think, er, like I shouldn't meant to have them, the, er - I don't know how to explain it. Um, er, I don't know how to explain. Like because it's not medical.

R. Yeah.

Fiona: Do you get what I mean?

Yeah.

Fiona: Like it's not, like it's not like having a tumour, because it's to do with your brain, but it's not life, you know like life threatening, but it's only you that can really control it. Now if it were epilepsy, you'd have tablets, wouldn't you, to control it, you'd be on medication to control it, but you can't take medication for this. It's more of.. it's yourself.

Even though you don't realise that you're getting it, which I can, I can see now why I were getting them, now that I've read the booklet, but it doesn't really tell you how, how to like stop it or how to train your brain or anything like that. It doesn't, because all I do now is, um, when I'm poorly,

R. Hmm

Fiona: Since, since that Friday, um, my k, er, my kidneys been hurting for a, er, a good couple of months, and now I'm debating myself are they actually hurting or am I making it up now, because if your brain can cause your body to do that without you knowing, now I'm thinking well do my kidneys actually hurt now? Or is it just in my head? And I'm making my kidneys hurt, do, do you get what I mean?

R. I do, really ... so you're feeling?...

Fiona: 'Yeah... uncertain, pretty much about everything now, it's like, just one of them things, you, you don't know what to do now. I don't. I, I don't have a clue what to do, I don't, I'm meant to go to doctors or. It, it, it's just like a constant battle with yourself, you know, um, thinking like, because the is about I think something's going to happen when I'm out'

Metaphor in bits/
emphasis organic
nature, interpret.
condition – brain

Can't explain or
define no label to
'name' it-
diagnosis

Validation? But
dilemma unable
to control it –
Tablet medical –
no available
medical
treatment, so
sense of cure –
see self as
fundamentally
flawed abnormal
deficient (relates
to illness
coherence)?

Helplessness –
no control alien
brain entity social
language

Poorly, mind
body dichotomy.
Uncertainty of
reality not trust
self and own
experiences –
not see pain as
subjective exp.
but a medical
physiolog cause.
Altered sense of
reality– very
unsettling, loss of
trust in own
experience or
instincts. Passive
external.
Uncertainty of
self/trust. Battle
fight anxiety
alone. Trying to
overcome anx -
iety element
Unpredictable,
unsafe. Self fight

APPENDIX L- Epistemology Statement

Rationale for the choice of Interpretative Phenomenological Analysis (IPA) and epistemological and ontological considerations.

Research derives knowledge from a basis of assumptions about the world and reality. Critically, the researcher's position of knowledge or beliefs largely influences the interpretation of the research. Hence, a reflexive process is necessary to consider one's own stance and assumptions about the world, in order to reduce potential influences.

Ontology and epistemology.

To better understand the basis of knowledge or assumptions that research may be based on, it is useful to consider the philosophical underpinnings of ontology and epistemology. Ontology refers to reality, the study of being in the world, and what can be known, the nature of existence (Willig, 2001). In other words, what we believe exists regarding the nature of society, and individuals in the world. Whereas, epistemology involves knowledge, how something can be known, what may be evidence or proof of knowing, and how knowledge is interpreted or observed (Willig, 2001).

A relativist position assumes that there is not a universality in truth, but that knowledge is relative to individual perception of, or experience in the world (Fletcher, 1996). On a wider scale, individual and cultural influences may refer to a 'field of being' with multiple interactions and interdependent relationships between society and the individual (Merleau-Ponty, 1962).

In contrast, a positivist epistemology assumes that direct observation in the form of measurement, empirical evidence, is necessary to believe or trust in knowledge about the world (Fletcher, 1996). It employs quantitative

methodology, which involves establishing a causal relationship to provide evidence of a particular truth. It relies on theoretical research and developing hypothesis. This is in line with a realist perspective of the world, existing independently of our perceptions or theories, and to be empirically discovered. Positivism is in stark contrast to relativist, with its more subjective interpretations of thoughts, feelings, and intuition (Indick, 2002). This research is allied to the relativist approach of qualitative methodology, which attempts to explore and understand experience at a more person-centred level.

The ontological and epistemological stance of the research.

Psychogenic syncope (PS), classified within MUS, is viewed from a lens which gravitates towards a psychiatric perspective in current health care (Lock, 1993; Bodenreider et al. 2004). However, MUS symptoms may present epistemological difficulties, due to their lack of a medical diagnosis (Lock, 1993). MUS cannot easily be categorized, or a causal relationship found for example, as in chronic fatigue (Erikson, et al. 2013). A result of this may be that individuals are not understood, in medical or social circles, and the term 'all in the head' is frequently implied (Ware, 1992; Parnas et al. 2013; Erikson et al. 2013). Equally, the Western epistemological view of mind-body separation may contribute to a reportedly fragmented sense of self (Bodenreider et al. 2004; Erikson et al. 2013). Research into PS, or PNES, or NEAD, is driven from neuropsychiatry, or neuroscience, which bases itself on empirical, or causal models of research (Bracken et al. 2012; Parnas et al, 2013). This, as a positivist orientation, focuses on 'faulty mechanisms' within the individual (Bracken et al. 2012). A further result of this may be a sense of self-doubt, which individuals may experience as related to their sense of reality, or shame related to stigma (Ware, 1992). According to Ware (1992), there is a paucity of meaningful language in which individuals may

understand, or explain their condition. It appears that the current epistemological methods in which to understand MUS, or PS, may be insufficient. Briefly, to focus on elements of consciousness, or loss of, which is a dimension in PS. It is argued that consciousness is a stream, a continuum, not fragmented phenomena, and neither discrete nor measurable (Parnas et al. 2012, Aragon, 2013). Thus, attempting to categorise symptoms of PS in the current epistemology may be unreasonable. PS is highly complex, and may be based on a fluctuating continuum of experiences, beliefs and feelings (Parnas, 2012).

Hence, a relativist stance was taken in this study in order to explore, and understand, individual experience from the complexity of a person-centred reality. Equally, there exists a sparsity of research into the real world experiences of people with PS. Hence, conclusively, the exploratory method of qualitative methodology aligned with the relativist position was chosen for this study (Smith, Flowers & Larkin, 2009).

The rationale for the choice of Interpretative Phenomenological Analysis (IPA).

Alternate methods of qualitative methodology were considered but were rejected on the following grounds.

The option of *thematic analysis* (Pope, Ziebland & Mays, 2000) was rejected as it aims to identify and analyse patterns to form categories of data, which is the basis of a reductionist approach (Braun and Clarke, 2008). So thematic analysis may not allow an exploration of individual experience, or meaning, to be interpreted at depth (Andersen, 2007).

Grounded theory (Glaser & Strauss, 1967) has the aim of generating theory, or extending knowledge by means of qualitative approaches, and data saturation (Willig, 2001). The development of theory was not the aim of this study, which was to explore individual experience. Also, the interviews employ systematic and sequential processes, so would be a more positivist approach to understanding phenomena (Willig, 2001).

Discourse analysis (Willig, 2001; 2008) analyses experience through language, centred in socio-cultural contexts, as opposed to individual lived experience. Its aim would be a construction of social reality using analysis of detailed linguistic data, for example words and sentence structure (Willig, 2008). The aim of this study is to understand phenomena or experience from a person-centred approach, possibly including non-verbal communication. Hence, this method would not be suitable, due to the central focus on language in discourse analysis.

Interpretative Phenomenological Analysis (IPA) was chosen as a method in which to attempt to understand individual experience and personal meaning of PS. Currently, it is proving invaluable in health psychology (Smith, 1999), so its methodology in exploring PS aligns with health-related research. IPA consists of three theoretical perspectives, phenomenology, hermeneutics and idiography. Phenomenology involves a method of research based on the philosophy of Husserl (1970) developed by Heidegger (1982), and Merleau-Ponty's (1962) 'lived world' experience. So, understanding of the experience of phenomena, such as PS, will be in relation to a unique personal perspective (Smith et al. 2009). Perspective may be the individual's beliefs and sense-making of their world, whether conscious or unconscious, their 'being in the world' (Smith, 2011, Merleau-Ponty, 1962, respectively). With regard to unconscious sense-making of experience, nuances, body language,

or intuitive interpretation may be employed in IPA, parallel with language (Husserl, 1970, Larkin, Watts & Clifton, 2006). Equally, the researcher's unconscious framework of analysis may have aspects that remain unidentifiable in the process of analysis, so the process may not be fully transparent (Lyons & Cole, 2007).

The double hermeneutic in IPA, occurs during the researcher's interpretation of the participant's experience (Smith & Osborn, 2003). This may be explained by a hermeneutic circularity in IPA interviews, as the researcher's values, biases, or understanding of the phenomena described by the participant, shapes the interpretation (Larkin, Watts & Clifton, 2006).

Awareness of this limitation is crucial in interpretative analysis, so peer review and supervision, parallel with reflective practice, may help to reduce this influence.

Idiography is the commitment to detail, with specific focus on the individual interpretation of experience, in situations, or events (Smith, 1999, Wagstaff et al. 2014). This iterative process, with the detail in repetitive contextual analysis, concurrent with reflectivity, highlights the highly person-centred approach (Smith & Osborn, 2007). Consequently, this methodology was considered the more suitable option in which to explore individual experience of the phenomena of PS. The self-regulation model (SRM, Leventhal et al. 2004) was integrated in an interview guide to underpin understanding of the phenomena of PS.

Reflexivity

The credibility of research findings is enhanced by the process of reflectivity, and by researcher awareness of the limitations inherent in the interpretation process (Mays & Pope, 2000). Thus, immersion in the data by the researcher

needs to be performed through reflective engagement with the text, and the double hermeneutic of interpretation (Wagstaff et al. 2014). The position of the researcher cannot be truly objective but a sense-making process occurs that resembles the participant's experience as far as is possible. Incorporated in this process is an acknowledgement of possible intuitive interpretation of unconscious aspects of the participant's description of experience (Osborn, 1994).

'Bracketing out' the limitations of the researcher's values, beliefs, or biases, in the interpretation may be achieved to some degree by the intuitive process, with 'intentional' iterative focus on one's own assumptions during analysis (Osborn, 1994 Laverly, 2003, respectively). Pragmatically, this may be assisted by using a reflective diary to acknowledge and consider the impact of the researcher's beliefs. Additionally, in this study, research supervision and three professionals ensured that interpretation was grounded in the data, to maintain validity. Also, peer discussion was utilised where possible for alternative interpretation.

The core reflections were related to the researcher's age, the rapport established with the participant or the presence of family intermittently during the interview, which may all have impacted on the participant's extent of disclosure and description of PS. Equally, how the researcher may have experienced 'fainting', or learning about 'blackouts' from observation in 'blackout' clinics may have impacted on interpretation of data. Additionally, it is possible for example, that projection may have occurred in the interviews where descriptions were felt more strongly by the researcher when trauma or distress were described, resulting in amplified interpretation of phenomena (Rizq, 2012). Equally, reflections occurred on the parallel processes in waiting for consent, or hoping for positive responses to research invitation, when

numerous participants declined. Emotions were identified in supervision, regarding disappointment of nonattendance or frequently postponed interviews.

Due to the sparsity of literature that explores the experiences of people diagnosed with psychogenic syncope; a qualitative method was chosen. This was deemed suitable for an open curiosity around people's experiences (Baker & Jakoby, 2000). In 'exploring' people's experiences, the approach is a phenomenological one, where the individual's meaning and understanding of their world is sought. This is in contrast to the positivist and realist approach employed in quantitative empirical research, which suggests that reality or phenomena can be measured, to find causal relationships or outcomes (Smith, Flowers & Larkin, 2009). In this paper, the preferred stance is relativist as a method of process, which uses a more person-centred approach. This type of research may be found in qualitative research where individual reality is subjective, and individual experiences may be explored.

APPENDIX M – Epistemology References

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APPENDIX N – Definitions of Specified Medical Terms

Classification of terms (summarised) used in studies definitions defined from:

The 'International Classification of Diseases' (ICD-10-CM, 2015) World Health Organization. *The ICD-10-CM Classification of Mental and Behavioural Disorders: Clinical Description and Diagnostic Guidelines*. Geneva: World Health Organization.

<http://apps.who.int/classifications/icd10/browse/2015/en#/F44>

F48.0. *Other neurotic disorders*

Neurasthenia (retained in ICD-10 due to continued use in some cultures)

“The mental fatigability is typically described as an unpleasant intrusion of distracting associations or recollections, difficulty in concentrating, and generally inefficient thinking. In the other type, the emphasis is on feelings of bodily or physical weakness and exhaustion after only minimal effort, accompanied by a feeling of muscular aches and pains and inability to relax. In both types a variety of other unpleasant physical feelings is common, such as dizziness, tension headaches, and feelings of general instability...”

F48.8. *Other specified neurotic disorders*

Psychogenic syncope

F45.0 *Somatization Disorder*

“The main features are multiple, recurrent and frequently changing physical symptoms of at least two years duration. Most patients have a long and complicated history of contact with both primary and specialist medical care services, during which many negative investigations or fruitless exploratory operations may have been carried out. The course of the disorder is chronic and fluctuating, and is often associated with disruption of social, interpersonal, and family behaviour...”

*F44. 0. *Dissociative [Conversion] Disorders*

“The common themes that are shared by dissociative or conversion disorders are a partial or complete loss of the normal integration between memories of the past, awareness of identity and immediate sensations, and control of bodily movements. All types of dissociative disorders tend to remit after a few

weeks or months, particularly if their onset is associated with a traumatic life event. These disorders have previously been classified as various types of "conversion hysteria". They are presumed to be psychogenic in origin, being associated closely in time with traumatic events, insoluble and intolerable problems, or disturbed relationships. In addition, there is evidence that the loss of function is an expression of emotional conflicts or needs. The symptoms may develop in close relationship to psychological stress, and often appear suddenly..."

F43.1 Post-Traumatic Stress Disorder (classified under F43. Reaction to severe stress).

"This category differs from others in that it includes disorders identifiable on the basis of not only symptoms and course but also the existence of one or other of two causative influences: an exceptionally stressful life event producing an acute stress reaction, or a significant life change leading to continued unpleasant circumstances that result in an adjustment disorder. Although less severe psychosocial stress ("life events") may precipitate the onset or contribute to the presentation of a very wide range of disorders classified elsewhere in this chapter, its etiological importance is not always clear and in each case will be found to depend on individual, often idiosyncratic, vulnerability, i.e. the life events are neither necessary nor sufficient to explain the occurrence and form of the disorder..."

G40.2. Temporal lobe epilepsy

"Attacks with alteration of consciousness, often with automatisms
Complex partial seizures developing into secondarily generalized seizures"

T74. Maltreatment Syndromes

T.74.1. Physical Abuse

T.74.2. Sexual Abuse

Medically Unexplained Symptoms (Unclassified)

Non-epileptic attack disorder (NEAD) (Unclassified)

Psychogenic non-epileptic attack disorder (PNES) (Unclassified)

Functional syncope (Unclassified)

Apparent syncope (Unclassified)

Dissociative seizures (Unclassified)

Psychogenic pseudo-syncope (Unclassified)

Non-cardiac syncope (Unclassified)

Non-epileptic seizures (Unclassified)

Pseudo-seizures (Unclassified)

Found in epilepsy online domains (October, 2014):

(<https://www.epilepsy.org.uk/info/diagnosis/non-epileptic-attack-disorder-head>)

“Non-epileptic seizures (NES) is a descriptive term for a diverse group of disorders which refers to paroxysmal events that can be mistaken for epilepsy, but are not due to an epileptic disorder”.

“Psychogenic Non-epileptic Seizures (PNES) is commonly classified as a dissociative phenomenon or conversion disorder. Proposed revision in DSM-V would reclassify PNES under “functional neurological symptom disorder”. This change hopes to incorporate a term that is used more often by neurologists and remove terms with prior negative connotation”

“Psychogenic Syncope: non traumatic T-LOC divided into syncope, epileptic seizures, psychogenic pseudo-syncope, - consciousness apparently lost. Of psychological mechanism. Two types of patients have to be included in the differential diagnosis of T-LOC. In both, patients are non-responsive and do not show normal motor control, implying that falls are common. In one type gross movements resemble epileptic seizures; these attacks have been described as ‘pseudo-epilepsy’, ‘non-epileptic seizures’, ‘psychogenic non-epileptic seizures’, and ‘non-epileptic attack disorder”

APPENDIX O - Reflective Statement

'Our emotional life maps our incompleteness: A creature without any needs would never have reasons for fear, or grief, or hope... people flee from their inner world of feeling, and from articulate mastery of their own emotional experiences'. (Nussbaum, 2002, p176)

I chose this area of research because I have always been interested in the concept of consciousness, and health psychology. Hence, to a degree, this project touched on both. There were many challenges to overcome in developing the project to its successful end. This reflective statement attempts to summarise the variety of experiences along the way.

This is my advice to others who are starting research. To enjoy the experience, to leave time to rework and be reflective about everything in the course of the project. It is helpful to be aware of the boundlessness of knowledge, that there is always something to add, an expanse of discovery, which is not obvious at first. Hence go steadfastly through, it is important to be aware about the overall experience and processes, as well as open to ideas and changes of direction in the research, where necessary.

The Systematic Literature Review

It became clear during initial scoping searches that this was a much debated, controversial and confusing area of research. This was mainly due to the numerous terms used for the condition. It was uncertain whether there were any similarities in presentation, or patient experience of PS. Literature discussed MUS and the apparent overlap among the variety of conditions. I had worked in a chronic fatigue hospital department, so I was aware of the condition as a MUS and problems associated with it for the patient, and for the clinician. The review was a lengthy painstaking process. I decided to search with the terms PS and PNES, as PNES appeared to be the closest in terminology and definition. It was arduous not to get drawn into the epilepsy

domain in the process and to sift through the confusion around the conditions. Hence, I had to refine the terminology and exclude a vast amount of factors as they were too extensive to include in one review. I was left wondering, as a professional looking into this area for the first time, feeling confused, how it may feel for the patient. Hence, I decided to attempt to identify the factors associated with PS in order to understand and reduce the confusion in this area. The review called for a fast learning curve, and remains a continuous learning process.

The Empirical Study

The development of the study

I have always wanted to apply the learning in psychology to the outside world, where it is useful; and health psychology is invaluable for this. I chose to do an IPA study because I am interested in people, their lives, their stories and their world. It is part of the phenomena of coexisting on this planet. I suppose this is a phenomenological perspective of life, which I was particularly unaware of, until I did this research. Equally, I was interested in the psychosocial aspects that might have been present with a medically unexplained condition. The project within cardiology presented itself due to the apparent lack of research in this specialisation. Also, there appeared to be an absence of IPA literature in this area. I had previously engaged with quantitative research, so wished to balance my research experience and learn from the process. I think that people being in a place of 'not understanding' interested me, and I wished to attempt to find out what was happening for them and what they thought would help. There was not a previous research pathway to draw from, so I spent a lot of time at the clinic observing the interactions, and the diagnostic process involving the staff, and the patients who were diagnosed with a psychogenic presentation. It was very

much unravelling a complex subject, due to the lack of understanding of the dynamic human condition. I chose 'psychogenic' rather than another term such as 'functional' because a charity¹⁷ that supplies educative information to people with unexplained blackouts uses the term 'psychogenic'. Also, their information leaflet was utilised in the blackout clinic for patients. Thus, I thought that this term was more appropriate for people, especially as it corresponded with the outpatient clinic. However, as research time passed I realised that I would choose another term in the future, one that is possibly less stigmatising.

I found the process of IPA fascinating, that it had depth in the concept of insight into experience, and utilised intuition, which I have always thought has been undervalued and under-researched. I believe it to be a part of the quantum phenomena of possible collective communication, which research is beginning to explore.

The Recruitment and Interview Process

Much was learnt and 'felt' within this stage of the process. There was a sense of 'impossibility' in recruitment in the blackout clinic; due to the unpredictability of people coming for appointments through the system. Consequently, the recruitment process was challenging for the team as a whole. Nevertheless, the final number, although small in quantity, appeared to give rich data. The journey with the participants who initially expressed interest was long. Very few potential participants declined outright to an invitation in the clinic, or to a returned requested telephone call. Many participants postponed, cancelled arranged meetings or did not attend a mutually agreed time. Also, there may have been staff selection bias of the participants. I began to reflect on feelings about this, the sense of 'waiting' was strong. I considered this a possible

¹⁷ 'Syncope Trust And Reflex anoxic Seizures', which offers patient information on 'psychogenic blackouts'

projection, or defence mechanism, in how they might have felt waiting in the system. Equally, I may have been seen as a part of that system. Also, the ambivalence in not giving a clear 'no' at the outset and their avoidance may parallel or explain their coping style and presentation with services. Staff frequently reported that people did not attend appointments. This may have been part of a wider psychosocial problem in feeling misunderstood, outside of the medical system, due to 'having' or 'being given' a stigma-related condition.

People had most likely seen many professionals about their condition and preferred to be left alone. Also, the telephone could be a difficult disembodied medium of communication. The reasons for so many participants declining appears to be quite extensive. I realised that disconnected phone numbers resonated with a sense of disconnection, almost like disconnecting the self from the world or society in a tangible way by not updating phone details in the system. Equally, this could be over interpretation on my part.

The fact that all of the consenting participants requested a home visit may have related to not being able to go out or feeling more in control at home, or that the hospital room was too clinical. Thus, those who opted for the hospital route, cancelled or 'did not attend'. At first, I felt disappointment that the majority did not simply say 'no' rather than postpone, or cancel appointments. There seemed a 'greyness', a sense of nothing definite about recruitment, which may have been related to participants' personal experiences of their condition.

The interviews in participants' homes felt like an honour, a privilege, with being let in to a secret world especially as they were very honest and open in talking about everything that mattered to them about PS. I observed some

psychosocial difficulties, which were not possible to include, or ethically appropriate. However, I had much to reflect upon and draw insight from, in the process, things that influenced their recovery and sense of confidence. I sometimes found myself 'afraid' to ask about the psychogenic aspect of diagnosis as it arose, if diagnosis was probable it was not always made clear to the participants by the clinic. I reflected on whether participants felt this ambivalence as uncertainty during the assessment process.

The fact that 5 out of 6 did have a close family member to support them, partner or parent, may have been unusual, as literature suggested this was not the case. However, one participant depended on going out to town, and appeared, in descriptions, to 'carry' the blackout as a part of a unique identity to facilitate positive social interaction. I felt that there were so many things to include in the write up, but I did not want to appear to speculate as an IPA beginner. Hence, I think that the study could have been a deeper, richer study with more time and experience. Time was a factor, as the recruitment process took months. I had hoped to interview people from the Asian British population to see whether they were coping differently, for better or for the worse, in their family and social environments. More of the Asian British potential participants declined outright, which may have been due to factors relating to culture not yet investigated. Hope was a key emotion and I learnt, in a sense, to 'not hope' when I invited people to take part, and was 'over the moon' if someone accepted (not on the telephone but afterwards). I found the participants to be kind, resilient, lovely people, who were keen to talk. I debriefed them verbally at the end of each interview, and referred one to psychology through the team, as she had requested.

A low emotional expression appeared noticeably present within one family, and I wondered whether this had anything to add to the presentation of PS, regarding perpetuation or management of emotion.

I notice during writing reflectively that words such as accept, avoidance, frustration hope, and disappointment in recruiting all resonate with the participants' accounts of emotion. Finally, the majority of participants stated 'you know' at the end of sentences. This may have been due to a need to be understood and have feeling or thoughts normalised and validated. I wished that the participants could meet each other to share experiences in order to potentially help each other via peer support.

The Strengths of the Project

I had patience with the process during recruitment, especially as time went on and more declined than accepted the invitation. I established good rapport with participants and the clinical team, which was a strength. Listening and being comfortable with pauses in the interviews was felt to be important to let participants reflect. This was not always easy as I felt I needed to interject with something helpful. Hence, there was an awareness of parallels with therapy, which I managed. I thought that I had good listening skills for people to express themselves in the interviews.

There are a number of things that I would have done differently in the design, with experience.

The Choice of Journal

One of the reasons for choosing the journal was the international access to a wide range of readers, as the majority of SLR findings came from international sources, and culture played a large part of somatically defined conditions. Also one that is cardiology related, as I had mailed another

blackout clinic and the consultant was interested in the results, and what to do about this population in his clinic. This patient group appears to be overlooked or underrepresented within cardiology literature, thus it may be useful to engage readers in cardiology specialisation. Equally, there appears to be a number of people that present with PS in blackout clinics across the country. The neurology route was my initial thinking around choice but there is already a large volume of literature. I thought that to integrate cardiology awareness into the umbrella of all the PS diagnoses terms may prove useful in the long term or trigger further research in cardiology in PS. Communication of research in this area may enhance psychological intervention as more researchers become involved.

Personal Reflections

Apart from a feeling of exhaustion and of being immersed in a wealth of new information coming from various sources, it has been highly valuable time in choosing which knowledge to accept or to keep for another time. There are reams of journals and books that will continue to provide enjoyment and interest. Overall, there was a sense of being 'all at sea' in the research journey, as I got deeper into learning and understanding it became clear that the discovery of knowledge was endless, there was always something to add that veered off course on relevant tangents, or not so relevant. Not unlike a beach with discoveries like grains of sand. It took a vast amount of personal discipline, effort, willpower and energy to persevere after an unexpected lengthy journey, incorporated with a final difficult recruitment process. The research in itself was important to me, as was the qualification, it became a challenge to test my limits. I have learnt that sometimes it is okay to give up, when many things are rather bleak, but indeed not on this occasion. However, the challenge appears to be very worthwhile, and, most of all I hope useful

'out there' somewhere, for someone. Finally, I have to use the word exciting about the research, and to be slightly poetic in the hope that it may provide 'a drop in the ocean' while striving for knowledge and understanding.

Other reflections

The idea of 'acting out' in psychodynamic terms was reflected upon as well as 'splitting'. However, following discussion with a psychodynamic-oriented professional, I decided that it was not useful to include it on this occasion, due to a lack of detailed patient background information. During analysis comments were made in text boxes as they helped to separate my own interpretation from the participants' language.

Subsequent to drawing a triangle in *Figure 2*, of Part Two, as it seemed to me that participants were separated from society, I was pleased to come across Zittoin, (2007) who describes triangles as symbolic asymmetrical relations, and social transmission, whereas symmetry identifies supportive cooperation.

At times I felt unintentionally like a 'detective' during the interviews, and reflected on participants' emphasis on 'seeing or hearing', and whether they felt that they needed to convince me that their condition was genuine. Other times I was concerned that participants had not been told that they had psychogenic syncope, which was followed by relief when participants referred to it. The effects of temporality in interviews caused me to 'look out for words' by the fifth or sixth interview. Fortunately, through reflection I was aware of this happening and deliberately attempted not to prompt the emerging themes from the accounts.

Also, I would have restructured the interview schedule to include less material upon hindsight, and importantly employed the more relevant 'IPQ-R' as a measure. I realised that the positivist viewpoint of studies in the review, or

equally relativist epistemology, may have influenced my interpretation of the data. The research itself seemed to grow, possibly out of proportion, but at the start I did not know anything about this subject and at first it appeared almost overwhelmingly complex.

I learnt a lot about 'somatisation' and thought that it may be over-medicalised as it appears to be a common experience for example, blushing, or a stress headache. It indicates that we know little about emotion or intuition and therefore make assumptions about human physical reality, which in the future I hope will change. I believe that this will improve with greater knowledge from quantum biological research.

Furthermore, I hope that with the increase of knowledge about humans on a more holistic level will come wisdom, not only about the mind, but about refined perception, sentience, intuitive empathy and emotional intelligence, so that millennia of the devaluation of women will cease.

We have a lot to learn from the Eastern interpretation of the body, emotion and wellbeing. Indeed, assimilating mindfulness into this age of white noise may engender peace at an individual level, at least to start, as people become more aware of themselves and consequently each other.

Finally, I felt it important to draw on other disciplines, such as anthropology, as well as medicine and psychology, for a wider perspective and understanding of a complex subject because no one discipline has the complete story about human existence.

Researcher free thinking around blackouts: bereavement different forms /
attachment styles / positive attention / strong / not depressed / isolated /
poorly – family history modelling / magic / external locus / out of control of
body / fight / hopeless / abandoned / ambulance / sudden /helpless / trauma /
kinaesthetic experience / experiential falling / body / primal / comforting floor
contact / earth / positive touch / body rests – dark eyes closed restful / switch
off / childlike feels like hiding / comfort of strangers / care about me / possum /
'theatres of the body' psychodynamic somatic illness / splitting / Freud /
Japanese Kabuki / consciousness / explain the unexplainable / quantum
biology and consciousness /

'It is necessary to build a complete map of our humanity, to traverse the territory as a whole, finding our way by listening to people and seeing beyond the symptom and the spoken word. At the moment we only view different segments of the map, which reduces communication and understanding across the disciplines. Discovery of our humanity will occur through mutual openness, curiosity, intuition and affinity. Then and only then may we understand ourselves as we really are' (BSHansen, 2015)