

Perspectives on Psychogenic Non-Epileptic Seizures

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Thesis Abstract

This thesis explores the perspectives of people on psychogenic non-epileptic seizures (PNES). It is presented in three separate papers: a systematic literature review; an empirical research paper and a critical reflection of the research process as a whole.

The systematic literature review aimed to provide a detailed understanding of stakeholder perspectives on PNES. A systematic search identified relevant studies that were subsequently synthesised using thematic analysis and the broader principles of narrative synthesis. Three broad themes relating to stakeholder perspectives were identified: the nature of PNES as a condition; diagnosis; and management and treatment issues. It was found that both patients and professionals experienced uncertainties in relation to understanding and managing the condition. This highlighted the need for further information and awareness of PNES and the development of clear treatment guidelines. Important differences in opinion were also identified between patients and professionals and consideration was given to how these may disrupt the development of effective partnerships in care. The research into patients' and families' perspectives was found to be lacking and further research was identified as being needed in this area.

The empirical paper reports an exploratory qualitative study that aimed to provide an in-depth understanding of the perceived treatment needs of patients with PNES. Semi-structured interviews were conducted and findings were analysed inductively using the principles of thematic analysis. Four key themes were identified: *return to normality*; *post-diagnostic limbo*; *uncertainty and apprehension about therapy*; and *need for validation*. Patients with PNES described clear goals for their recovery and clear ideas about their treatment needs. However, following their diagnosis, many felt caught in 'limbo' due to uncertainties about their diagnosis and as a result of a lack of post-diagnostic support. Being in 'limbo' also linked to patients' uncertainties about psychology meeting their needs and for some there was apprehension about the potential negative consequences of therapy. The clinical implications of the research are discussed and recommendations for future research are made.

The third paper is a critical reflection of the research process as a whole. It provides an overview and evaluation of the first two papers and personal reflections of the lead researcher are offered throughout. Implications for further research and clinical practice are offered and a summary of the research as a whole is offered.

Declaration and Copyright Statement

Declaration

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What do people think about Psychogenic Non-Epileptic Seizures? A Systematic Review of Stakeholder Perspectives

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Abstract

Purpose

Many people are involved in the care of psychogenic non-epileptic seizures (PNES) and the varying perspectives of these 'stakeholders' can have an important influence on the management of this condition. A systematic review was conducted to provide a detailed understanding of stakeholder perspectives on PNES, to inform the future development of patient-centred services.

Method

A systematic search was made of the Embase, Medline and PsycINFO databases between 1980 and 4th April 2012 to identify relevant studies. These studies were reviewed and their quality was assessed. Findings were organised according to the principles of narrative synthesis, using themes to represent the important relationships in the data.

Results

Twenty-five quantitative and qualitative studies were identified as being suitable for inclusion in the review. Three broad themes relating to stakeholder perspectives were identified: the nature of PNES as a condition; diagnosis; and management and treatment issues. Important differences in opinion regarding control and terminology were identified between patients and professionals. Uncertainty in relation to understanding the condition and progressing with treatment was felt by both patients and professionals. The research into patients' perspectives was lacking and no research existed into the perspectives of families.

Conclusion

Differences in opinion between stakeholders may impact on therapeutic relationships and therefore needs to be addressed to ensure the development of effective partnerships of care. Uncertainty reported by stakeholders highlights the need for further information, awareness and clear guidelines for the treatment and management of PNES. Further research is needed on the perspectives of patients with PNES and their families.

Keywords: Psychogenic non-epileptic seizures; Systematic review; Perspectives; Views; Stakeholders; Narrative synthesis.

Introduction

Psychogenic non-epileptic seizures (PNES) are episodes of altered movement, emotion, sensation or experience, which appear similar to epileptic seizures but are not accompanied by the associated electrical brain activity.¹ Prevalence of PNES has been estimated at between 2 and 33 per 100,000,² with PNES patients representing between 9-50% of those seen in epilepsy services.³ Providing an accurate diagnosis of PNES can be challenging^{4,5} with diagnostic delays of several years being typical.^{6,7} Misdiagnosis of epilepsy is common in this group and patients are often exposed to multiple unnecessary investigations, outpatient visits and medical treatments at great personal and economic cost.^{8,9}

Several detailed accounts of the factors involved in the development and maintenance of PNES have been developed¹⁰⁻¹² but a widely accepted and empirically established understanding of the condition remains lacking.¹³ As a result, the most effective way of managing and treating the condition is unknown,¹⁴ meaning that nearly three-quarters of patients continue to experience seizures at follow up.¹⁵ Psychological therapy is most often considered the treatment of choice for PNES¹⁶ but there is a lack of sufficiently rigorous treatment trials in this area.^{17,18}

Understanding the perspectives of service users, carers and the public is increasingly regarded as a central part of developing patient-centred services.¹⁹ In addition to patients themselves, many different people are involved in managing PNES, including health professionals such as neurologists, general practitioners, nurses, psychiatrists, psychologists and psychotherapists, and more informal carers such as family and friends. How these different stakeholders perceive PNES, including their nature, diagnosis, management and treatment, can have a significant impact on the care that is provided for this condition. As such, it is crucial to have a detailed understanding of these different perspectives if effective and accessible services for patients with PNES

are to be developed. At present, however, there are no published reviews of PNES patients' perspectives or those of other stakeholders involved in managing this condition. In this paper a narrative synthesis of qualitative and quantitative research in this area is presented, with a view to understanding the nature and cohesiveness of different stakeholders' views on the condition. The clinical implications of this research are considered and areas for further investigation are identified.

Methods

Inclusion/Exclusion Criteria

To identify published studies investigating stakeholder perspectives in relation to PNES, a systematic search of journal articles' titles and abstracts was made using the Medline, PsycINFO and Embase databases between the dates of 1980 and 4th April 2012. For the purposes of this review, stakeholders were defined as: patients with PNES; broader patient groups; professional providers of care such as neurologists, general practitioners (GPs) etc.; families and unpaid carers of PNES patients; professional carers or personal assistants; and the general public. Perspectives were defined broadly to include perceptions, views, attitudes, experiences, and/or opinions relating to PNES and different aspects of the condition, such as its understanding, diagnosis, management and treatment. Both quantitative and qualitative studies were included to accommodate what was anticipated to be a very broad area of research. Only primary research articles were included; dissertations, opinion pieces, book chapters and literature reviews were all excluded, as were single case studies and studies where a full account of the research was unavailable (e.g. research reported in conference abstracts).

Search Strategy

A broad range of terms is used by academics and professionals to refer to PNES.²⁰ A flexible adjacency search was therefore used, combining a list of potential descriptors (e.g., "non-epileptic", "dissociative", "psychogenic") and a list of relevant symptom terms (e.g., "seizure", "convulsion", "attack"). The results of this adjacency search were combined with the results of a second search that included more specific terms

commonly used to refer to PNES (e.g., “pseudoseizures”, “psychogenic non-epileptic seizures”). The combined results of these initial searches were then searched using terms that related to perspectives (e.g., “perspective”, “view”, “perception”, “attitude”). Full details of the search strategy are outlined in Appendix 2. All abstracts from the initial searches were read and papers that potentially met inclusion criteria were identified. These papers were then read in full and their reference lists and electronic citations were checked for further relevant papers not identified by the initial search.

Quality Assessment of Studies

An assessment of the quality of the included studies was completed. The Critical Appraisal Skills Programme (CASP) checklist²¹ was used for the quality assessment of studies that were primarily qualitative in their methodology and analysis. This checklist comprises ten questions pertaining to principles of rigour, credibility and relevance in qualitative research. For primarily quantitative studies, the Standard Quality Assessment Criteria for Evaluating Primary Research Papers²² was used. This is a fourteen point checklist with ratings covering study design, method, subject characteristics, outcome and conclusions. In line with guidance for carrying out narrative synthesis,²³ the quality assessment was used as a framework for highlighting the strengths and weaknesses of the included studies and not as a basis for exclusion.

Data Collection and Synthesis

The results of the studies were synthesised using principles of narrative synthesis.²³ This is an iterative process involving several stages. Data concerning study characteristics, sample, design and key findings were extracted and tabulated, which aided in the identification of patterns across the data and the development of a preliminary synthesis. Translation of data from quantitative to qualitative form was completed to create a ‘common rubric’. Results of the studies were then analysed using thematic analysis and relationships between themes were developed through the use of idea webbing. The robustness of the synthesis was continually assessed through critical reflection.

Results

Characteristics of the Included Studies

The process of identifying relevant studies is shown in Figure 1. The systematic database search identified 425 unique journal articles, of which 44 papers were read in full to establish whether they met inclusion criteria. From these, 22 were identified as relevant; the other 22 were either not relevant or did not meet inclusion criteria.

Three further papers were identified from reference lists and through forward citation searching of potentially relevant papers.

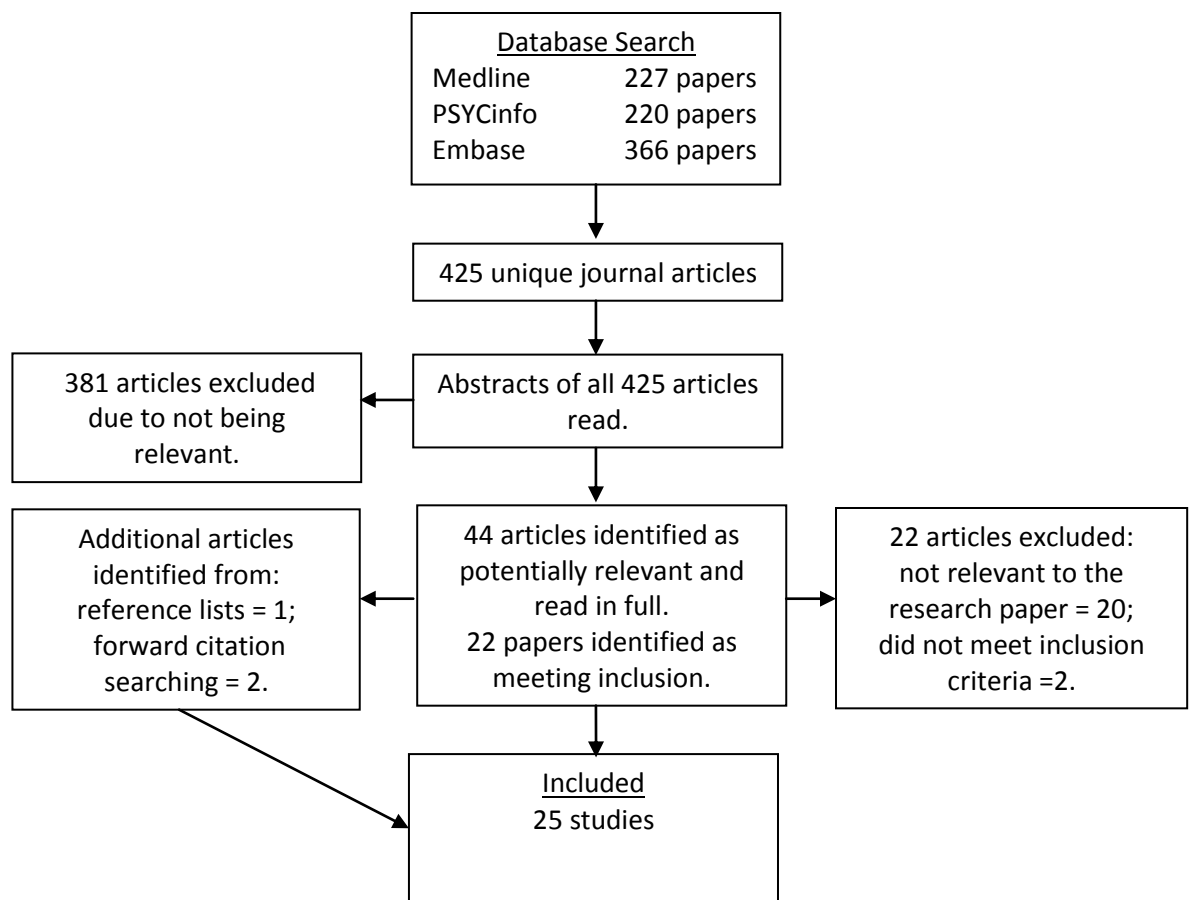


Figure 1: Process of identifying studies for inclusion in the review.

Twenty-five studies were included in the review. Ten studies included perspectives of patients with PNES, one study explored perspectives of general neurology patients and 15 studies focused on perspectives of health professionals including neurologists, psychiatrists, emergency physicians, general practitioners, neurophysiology technicians, nurses, ambulance crew, health care assistants, psychotherapists and clinical psychologists. The study characteristics are shown in Tables 1 and 2.

Table 1: Characteristics of quantitative studies included in the review.

Author, Year and Country	Purpose of study (pertaining to perspectives)	Sample Size and Characteristics	Research Design and Data Analysis	Key Findings (pertaining to perspectives)	Quality Rating
Schachter et al.²⁴ (1996) USA	Determine physicians perceptions of provocative tests (PT) for the diagnosis of PNES (within a wider study of looking at the use of PT).	426 physicians (43% response rate). Characteristics of sample not described.	Design: Cross-sectional questionnaire study. Analysis: Chi square.	1. Physicians' perceptions of both usefulness and patients' acceptance of the technique determined whether PT was routinely used. 2. A third of physicians thought inducing seizures posed an ethical conflict.	68%
Stagno & Smith²⁵ (1996) UK	Determine perceptions of induction procedures amongst providers (within a wider study investigating the use of induction procedures).	74 providers (62% response rate). Providers: 42 physicians, 31 nurses, and 1 neurophysiology technician.	Design: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. Majority of centres used the procedure yet an agreed standard of care was hard to identify. 2. Concerns regarding PT related to reliability and ethical issues. 3. In centres where PT was not used, neurologists commonly stated this was due to reliability issues but nurses most often stated this was due to ethical issues.	83%
Ettinger et al.²⁶ (1999a) USA	Develop a profile of the characteristics of patients with PNES and determine how these characteristics relate to outcome.	56 patients with PNES (74% participation rate). 40 females: 16 males. Age range: 14-61 years.	Design: Retrospective study using a 23 item structured questionnaire (administered by telephone). Analysis: Chi square and T-test.	1. The majority of patients reported believing diagnosis. 2. Anger at diagnosis did not predict poor prognosis. 3. More patients reported relief than anger at the diagnosis. 4. Outcome was predicted by positive belief in the diagnosis.	95%
Ettinger et al.²⁷ (1999b) USA	Examine the outcomes for patients with PNES and identify which variables predict outcome	43 patients with PNES (78% participation rate). 39 females: 4 males. Age range: 14-61 years.	Design: Retrospective study using a 40 item structured questionnaire (administered by telephone). Analysis: Chi square and correlation.	1. Patients most frequent reactions to diagnosis were sadness and anger. 2. The majority of patients agreed with their diagnosis, however many reported feeling uncertain about it. 3. Most patients were hopeful of change, however patients' optimism was variable.	95%

Author, Year and Country	Purpose of study (pertaining to perspectives)	Sample Size and Characteristics	Research Design and Data Analysis	Key Findings (pertaining to perspectives)	Quality Rating
Benbadis et al.²⁸ (2000) USA	Gain neurologists' views of driving restrictions (within a wider study of investigating risk of driving in patients with PNES).	37 neurologists (45% response rate) and 20 patients with PNES. Patients- 17 females: 3 males. Patients - Age range: 16-67 years.	Design: Mixed cross-sectional questionnaire and observational study. Analysis: Chi square.	1. Variability reported in neurologists' attitudes regarding driving privileges, with the majority applying the same restrictions as epilepsy. 2. A third of neurologists felt no restrictions should apply and a fifth preferred to decide on a case by case basis.	68%
Harden et al.²⁹ (2003) USA	Understand whether neurologists and psychiatrists differ in their views of the diagnosis and management of PNES.	50 neurologists and 75 psychiatrists (99% response rate).	Design: Cross-sectional questionnaire study. Analysis: Chi square.	1. Significant difference in opinion between neurologists and psychiatrists regarding the accuracy of video-electroencephalography (EEG) for diagnosis. 2. Neurologists and psychiatrists perceived that patients "fall through the cracks" due to patients' psychopathology and doctors' mistakes.	91%
Carton et al.³⁰ (2003) UK	Assess patients' understanding and reaction to diagnosis of PNES and identify which factors have an impact on outcome.	84 patients with PNES (73% participation rate). 65 females: 19 males. Age range: 16-64 years. GPs of 78 participants responded (92% response rate).	Design: Cross-sectional questionnaire study. Analysis: Content analysis and chi square.	1. Majority of patients did not have a good understanding of PNES. 2. Patients typically accepted the diagnosis. 3. PNES reportedly had a negative psychosocial impact. 4. Perceptions of psychological follow-up varied. 5. Majority of GPs agreed with diagnosis; GPs who disagreed often continued anti-epileptic medication.	77%
Stone et al.³¹ (2003) UK	Determine the acceptability and offensiveness of labels for seizures of unexplained origin in neurology outpatients.	102 general neurology outpatients (80% participation rate). 61 females: 42 males. Age range: 18-62 years.	Design: Cross-sectional structured interview study. Analysis: Chi square.	1. Terms deemed least offensive were: epilepsy-related; functional; and stress. 2. 'All in the mind' deemed most offensive term, followed by hysterical and pseudo. 3. Many labels used for psychogenic seizures are perceived as offensive by patients.	100%
Oto et al.³² (2005) UK	Understand male and female perspectives of diagnosis (within wider study of determining whether gender distinguishes those with PNES).	160 patients with PNES (epilepsy included). 117 females: 43 males. Age mean: Males – 41 years and Females – 35 years.	Design: Prospective study using semi-structured interview. Analysis: Odds ratio and chi square.	1. Men were more likely to report a risk factor commonly associated with epilepsy. 2. Most patients accepted the diagnosis of PNES and no gender differences existed in acceptance. 3. Majority of patients believed in a physical cause for their seizures. 4. Carers of men were less likely to accept the diagnosis than carers of women.	73%

Author, Year and Country	Purpose of study (pertaining to perspectives)	Sample Size and Characteristics	Research Design and Data Analysis	Key Findings (pertaining to perspectives)	Quality Rating
O'Sullivan et al.³³ (2006) UK	Assess GPs' opinions regarding diagnosis and management of PNES.	GPs (demographics not described) of 23 patients diagnosed with PNES (epilepsy co-morbidity included). 10 females: 13 males. Age range: 18-56 years.	Design: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. A third of GPs did not agree with the PNES diagnosis. 2. Minority of GPs viewed psychology as a beneficial treatment. 3. GPs admitted poor understanding and lack of knowledge of how to manage PNES. 4. There existed a variation in views of which professionals should follow up patients with PNES.	89%
LaFrance et al.³⁴ (2008) USA	Determine what constitutes treatment as usual for PNES from the perspectives of experienced clinicians.	317 physicians (18% response rate), including: epileptologists (66%); neurologists (10%); neuropsychologists (8%); nurses (6%); and other (10%).	Design: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. Preferred method of diagnosis was video EEG and long term monitoring. 2. Preferred term is 'non-epileptic seizures' 3. Preferred treatment is psychotherapy. 4. Neurologist's role was perceived not to stop following the diagnosis.	89%
Shneker & Elliott³⁵ (2008) USA	Gain an understanding of attitudes and beliefs amongst non-neurologist physicians.	159 physicians (22% response rate). Speciality: family medicine (31%); internal medicine (39%); and emergency medicine (30%). 72 females: 87 males.	Design: Cross-sectional survey. Analysis: Chi square.	1. Variable confidence in the diagnosis of PNES based on a number of techniques; EEG perceived as not always necessary. 2. Professional support for the term 'pseudoseizures' and there was a common belief that seizures are voluntary in this patient group. 3. Patients were perceived to not accept their diagnosis. 4. Psychotherapy regarded as best treatment.	91%
Specht & Thorbecke³⁶ (2009) Germany	Obtain the opinion of neurologists on driving recommendations for patients with PNES.	34 neurologists (82.9% response rate of those identified). Characteristics not described.	Design: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. Preference for individual assessment of driving ability. 2. All neurologists supported some form of driving restrictions for patients with PNES.	83%
Hall-Patch et al.³⁷ (2010) UK	Evaluate acceptability and short-term effectiveness of a communication strategy for the diagnosis of PNES.	50 patients with PNES completed telephone interview (89% participation rate). Of these, 72% completed questionnaires and 98% completed follow-up. 90% females: 10% males. Age range: 17-69 years.	Design: Semi-structured telephone interview and psychometrics. Analysis: Chi square.	1. Patients viewed the communication strategy as acceptable. 2. Majority of patients were satisfied with the consultation during diagnosis. 3. More emotional causes than physical causes were endorsed following the use of communication strategy.	95%

Author, Year and Country	Purpose of study (pertaining to perspectives)	Sample Size and Characteristics	Research Design and Data Analysis	Key Findings (pertaining to perspectives)	Quality Rating
Mayor et al.³⁸ (2011) UK	Describe the care currently received by patients with PNES in the UK and Ireland.	130 health professionals (< 5.8% response rate). 64% consultant neurologists; 13.6% specialist registrar, 20% nurses, 2.4% clinical psychologists.	Design: Cross sectional internet-based questionnaire study. Analysis: Descriptive statistics and content analysis of open ended questions.	1. Preference for 'non-epileptic' term. 2. Psychotherapy regarded as treatment of choice. 3. Majority of professionals who diagnosed patients saw their role as providing support post-diagnosis. 4. Professionals reported 'gaps' in their knowledge of PNES and they supported the development of treatment pathways.	94%
Morrison & Razvi³⁹ (2011) UK	Describe current practice amongst neurologists and epilepsy specialists in the UK regarding their advice about driving.	54 respondents (0.04% response rate) recruited via email. 72% consultant neurologists, 24% specialist registrars, 4% clinicians with an interest in neurology	Design: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. Wide variation in practice regarding driving restrictions. 2. Majority of specialists endorsed restrictions similar to those for epilepsy. 3. Non-specialists agreed similarly with applying the same restrictions as epilepsy or less restrictive.	89%
Worsely et al.⁴⁰ (2011) UK	Describe the illness perceptions of health care staff toward epilepsy and PNES.	30 emergency care staff (27 emergency department nurses, and 3 ambulance crew members) and 31 neuroscience ward staff (20 neurophysiology technicians, 8 nurses and 3 health care assistants).	Design: Cross-sectional questionnaire study. Analysis: Wilcoxon signed ranks and Mann-Whitney U test.	1. Health care workers were more uncertain of PNES than epilepsy. 2. Epilepsy viewed as more chronic than PNES. 3. Belief that patients with PNES have more control than epilepsy patients. 4. Psychological causes attributed as most important for PNES.	91%
Whitehead & Reuber⁴¹ (2012) UK	Understand the illness perceptions of neurologists and psychiatrists of epilepsy and PNES.	45 neurologists (14 general neurologists, 31 epilepsy specialists) and 40 psychiatrists (11 general, 11 liaison, 12 neuropsychiatrists).	Method: Cross-sectional questionnaire study. Analysis: Wilcoxon signed ranks and Mann-Whitney U test.	1. Psychiatrists perceived epilepsy as more chronic than PNES; this view was not shared by neurologists. 2. Epilepsy perceived to be better understood than PNES. 3. Physicians were significantly more likely to endorse psychological factors for PNES. 4. PNES viewed as more controllable by patients.	86%
Sahaya et al.⁴² (2012) USA	Assess the opinion of health care providers towards PNES.	417 health care providers (337 primary care physicians, 60 nurses and 20 neurology physicians).	Method: Cross-sectional questionnaire study. Analysis: Descriptive statistics only.	1. 'Non-epileptic seizure' is the preferred term. 2. Two-thirds of the total respondents supported the involuntary nature of seizures, however, nearly half of nurses surveyed thought patients "faked" seizures. 3. Neurologists and nurses reported confidence in managing patients with PNES. 4. Most favoured driving restrictions for patients.	83%

Table 2: Characteristics of qualitative studies included in the review.

Author, Year and Country	Purpose of study (pertaining to perspectives)	Sample Size and Characteristics	Research Design and Data Analysis	Key Findings (pertaining to perspectives)	Quality Rating
Green et al.⁴³ (2004) Canada	Investigate illness representations of patients with PNES in relation to Leventhal's self regulation model.	9 patients with PNES. 5 females, 4 males. Age range: 30-65 years.	Design: Qualitative semi-structured interview study. Analysis: Interpretive Phenomenological Analysis.	1. Uncertainty in patients' accounts of PNES. 2. Patient's confusion about their experience, their condition and its cause. 3. Lack of specific ideas about control or cure of PNES. 4. Patient's viewed psychological conditions as less genuine than physical. 5. Patients' acceptance of their situation and others acceptance and understanding were identified as important themes. 6. Illness identity needed for patients to have definite ideas about aspects of the self regulation model.	85%
Thompson et al.⁴⁴ (2009) UK	Provide insight into the experience of receiving the diagnosis of PNES from a patients' perspective.	8 female patients. Ages ranging from twenties to sixties (specific ages not reported)	Design: Qualitative semi-structured interview study. Analysis: Interpretive Phenomenological Analysis.	1. Main reported themes: the experience of living with PNES; label and understanding; being left in limbo land; doubt and certainty; feeling like a human being again; emotional impact of diagnosis. 2. Ability to integrate the diagnosis into a personal narrative was key in acceptance of the diagnosis. 3. Time and resources were identified as key to patient's understanding their diagnosis.	90%
Karterud et al.⁴⁵ (2010) Norway	Describe patients' experiences when diagnosed with PNES.	10 patients with PNES who had a past diagnosis of epilepsy. 6 females: 4 males. Age range: 16-61 years.	Design: Qualitative semi-structured interview study. Analysis: Phenomenological approach.	1. Change in diagnosis challenged patients due to threat to identity and transfer of responsibility. 2. Diagnosis may be stressful if the patient's emotional problems have not been acknowledged or understood. 3. Patients' reactions to diagnosis varied including: relief, fear, aggression, anger, disappointment and shame. 4. Acknowledging patient's own understanding of condition may be useful during the diagnostic process.	80%

Quinn et al.⁴⁶ (2010) Australia	Investigate the understanding and experience of therapists who treat people with PNES.	Therapists (five psychiatrists, two psychologists and one mental health nurse) experienced treating patients with PNES. 3 females: 5 males. Age: 7 participants were older than 40 years.	Design: Qualitative semi-structured interview study. Analysis: Grounded Theory approach.	1. PNES conceptualised as nonverbal communication which evolves in systems where verbal expression is restricted and nonverbal communication reinforced. 2. Lack of trauma history was perceived as needing a shorter involvement focusing on empowerment and stress. 3. Patients experiencing PNES within the context of longstanding difficulties and interpersonal trauma were perceived to need exploration of history and enhancement of interpersonal and self skills. 4. Clinicians experienced challenges in feeling confused and tolerating uncertainty.	100%
Dickinson et al.⁴⁷ (2011) Canada	Investigate how patients with PNES make sense of their illness experiences.	5 patients with PNES. 3 females: 2 males. Age range: 30-39 years.	Design: Qualitative semi-structured interview study. Analysis: Thematic Content Analysis.	1. Those who had incorporated epilepsy as an 'illness prototype' had greater restrictions on their lives. 2. Patients' illness prototypes were associated with treatment expectations. 3. Patients with a psychosocial explanatory model were receptive of psychotherapeutic treatment.	85%
Baxter et al.⁴⁸ (2012) UK	Explore patients' perceptions related to a brief psycho-educational intervention for PNES.	12 patients with PNES (11 completers and 1 non-completer). 8 females: 4 males. Age range: 19-54 years.	Design: Qualitative semi-structured interview study. Analysis: Thematic analysis.	1. Main themes: getting answers; understanding the link with emotion; seeking a physiological explanation for onset; doubting the diagnosis; the role of medication; and the way forward. 2. Interventions need to increase understanding of links with emotions and psychological causation.	90%

Results of Quality Assessment

The qualitative studies were of good quality according to the criteria set out in the CASP assessment tool, with scores ranging between 80-100% concordance. The standard most frequently not met during the quality assessment of qualitative papers was in the area of reflexivity in research, which was deemed not to have been described sufficiently in four of the six qualitative papers. A full account of ethical issues was also absent from two of the six papers. Full details of the quality assessments for the qualitative studies are set out in Appendix 3. The quality ratings were rated by a second researcher, with 97% agreement across all of the qualitative studies.

There was more variability in the quality of the quantitative studies, with scores ranging between 68-100% concordance and significant limitations were identified in some studies. The areas that often did not meet the quality criteria were controlling of confounding variables; sample selection; and poor response rates. Although no papers were excluded on the basis of quality, the limitations of these papers were considered during the data synthesis. The quality assessments for the quantitative studies are detailed in Appendix 4. A subset of eight quantitative papers was rated by a second researcher, with 92% agreement.

Results of Narrative Synthesis

The narrative synthesis resulted in the identification of three broad themes and a number of sub-themes relevant to stakeholders' perspectives.

Theme 1: Perspectives on the nature of PNES as a condition

Perceptions of the experience and control of seizures

Few studies have explored the subjective experience of PNES. One qualitative study reported that patients with PNES gave unclear and complex accounts that varied considerably between patients.⁴³ One interview study, limited by its lack of male participants, captured patients' descriptions of their episodes as having a strange and unreal quality during which they felt helpless, overpowered and out of control.⁴⁴ This latter perception of loss of control is consistent with other studies. One qualitative

study found that most of the nine patients reported having few ways of controlling their seizures⁴³ and a rigorous quantitative study reported that patients experienced their condition as unpredictable.³⁷

Patients' perceived lack of control contrasts with the findings of two quantitative studies of neurologists, psychiatrists, neuroscience and emergency health care staff, who perceived that patients with PNES had more control over seizures than epilepsy patients.^{40,41} A further high quality quantitative study reported that emergency physicians viewed PNES as being voluntarily induced.³⁵ In a similar study, this belief was also present amongst a significant proportion of nurses, although this perspective was generally not shared by the primary care physicians and neurologists also surveyed.⁴² Given the apparent disparity that can exist between patient and professional views about the controllability of seizures, it is perhaps unsurprising that patients with PNES have reported feeling doubted by professionals and significant others in interview studies.^{43,44}

Perceptions of severity and prognosis

Patients' views about the severity of their condition are under-represented in the research, although one interview study reported that some of the eight participants with PNES perceived their condition to be less severe than epilepsy.⁴⁴ In the aforementioned studies investigating illness perceptions in health professionals, there was a general perception that PNES was less chronic than epilepsy; however, this view was not shared by neurologists, who perceived little difference.^{40,41} In terms of recovery, a high quality cross-sectional study of patients with PNES found that 57% reported feeling optimistic about recovery, although the remainder of patients were not hopeful or uncertain that their condition would improve.²⁷ The opposite was found in a less rigorous qualitative study of nine patients with PNES, where most often resignation to living with the condition was reported and only a minority reported optimism about recovery.⁴³ Health professionals' views of prognosis mirrored the uncertainty of patients. In one robust survey, general and emergency physicians varied in their view of prognosis and only 21% identified with a recovery rate above fifty percent for patients with PNES.³⁵

Impact of seizures

Across three studies^{37,40,41} patients with PNES and health professionals had similarly negative ratings on the 'consequences' sub-scale of the Illness Perception Questionnaire-Revised⁴⁹ that measured the expected effects and outcome of PNES. The perceived negative impact of PNES on patients' lives was also found in other studies. Typical consequences of the condition discussed were: reduced emotional wellbeing;⁴⁴ loss of work and income;^{30,48} loss of independence;^{44,48} loss of role;⁴⁴ loss of confidence;³⁰ and negative consequences for families.⁴⁸ Patients with PNES have also described feeling "trapped"⁴⁴ and that living with PNES can be isolating and lonely.^{30,43 44,47,48} Lack of social contact was identified as detrimental by patients in one small interview study⁴⁷ and another qualitative study found that some patients linked isolation to feeling doubted by others.⁴⁴ In one interview study, degree of restriction was associated with patients' illness models, with physical models being associated with more social isolation than psychological models; patients also perceived that they experienced restrictions as a result of constraints imposed by their family⁴⁷, although these conclusions are from a study of only five patients. Similarly, restrictions for patients with PNES were supported by professionals in relation to driving across several studies.^{28,35,36,39,42}

Understanding of PNES

None of the PNES patients in two qualitative studies reported having prior knowledge of the condition before diagnosis.^{43,47} Even after diagnosis, patients reported confusion about diagnostic information,^{27,44,48} which continued in one study despite psychoeducational intervention focused on increasing understanding.⁴⁸ Patients' difficulties in identifying and understanding the causes and triggers for their condition were widely reported.^{30,43-45,48} Reasons reported by patients for this difficulty were understanding how a physical episode could be caused by emotional factors⁴⁸ and the lack of a temporal relationship between onset and potential triggers.³⁰ One small interview study noted that patients' lack of understanding about the cause of their condition was separate from the presence of potential causal explanations.⁴⁷ Across two interview studies, patients with PNES described difficulties moving forward

without an understanding of the cause of their seizures,⁴⁴ and being able to cope was linked to identifying precipitants of the condition.⁴⁵

Six studies reported that patients with PNES had varied beliefs regarding whether psychological or physical factors caused their condition.^{30,32,37,43,47,48} Beliefs in a physical cause were maintained for a minority of patients despite interventions aimed at altering such attributions about PNES.^{37,48} Physical causes perceived by PNES patients included epilepsy,^{30,32,47} physical co-morbidities⁴⁷ and physical injury.^{37,47} In one prospective study, men with PNES were reportedly more likely to identify risk factors associated with epilepsy.³² Where PNES patients were able to identify psychological factors associated with their condition, these included: emotional state,^{30,37} the “subconscious”,⁴⁵ conflict and stress,^{30,37,43-45} past traumatic experiences;^{43,44} long-standing life problems;⁴⁵ witnessing epilepsy;⁴⁷ and recent life stresses.^{43,44,47}

PNES was understood significantly less than epilepsy in two studies investigating health professionals’ perceptions of the condition.^{40,41} Only one study has obtained an in-depth understanding of professionals’ perceptions of the causes of PNES, which was a high quality interview study with therapists.⁴⁶ Therapists perceived PNES as either stress related or a complex presentation of attachment difficulties and psychiatric co-morbidity, occurring in the context of interpersonal trauma. Therapists viewed PNES as a functional communication that arose from a lack of skills in gaining relief in other ways. Two other studies investigated health professionals’ understanding of causes but in less depth. In the first, there was consistency between neurologists’ and psychiatrists’ views that PNES was mainly or entirely attributable to psychological factors, with neurologists being more likely to endorse a wholly psychological cause.⁴¹ In the second study, neuroscience ward staff and emergency health professionals were most likely to attribute PNES to mainly psychological or a combination of physical and psychological causes.⁴⁰ Across these two studies, the causal factors most identified as relevant to PNES by professionals were: experiences of abuse, patients’ personality, stress or worry, and emotional state.^{40,41}

Theme 2: Perspectives on the diagnosis of PNES

Labelling

In two qualitative interview studies, the need for a diagnostic label was reported by patients,^{43,44} and was linked to a need for validation.⁴⁴ Only one study has explored patients' opinions regarding diagnostic terms for PNES, however this high quality cross-sectional study represented the views of general neurology patients rather than PNES patients per se.³¹ These patients reported that terms relating to 'epilepsy', 'stress' and 'functional' were least offensive, whereas the terms 'all in the mind', 'hysterical' and 'pseudoseizures' were considered most offensive. In contrast, evidence from two studies suggests that 85% of physicians³⁵ and 32% of in-patient nurses⁴² perceive 'pseudoseizures' to be an acceptable term. Four surveys of professionals' preferences for terminology identified most support for the terms 'nonepileptic attacks'³⁸ and 'nonepileptic seizures',^{24,34,42} which were perceived as moderately offensive in the patient study.³¹

Diagnostic approaches

Three studies identified that professionals support a number of approaches for diagnosing PNES, including: symptom provocation, electroencephalography (EEG), clinical history and observation.^{34,35,38} The perceived value of these specific approaches differed within and between professional groups. In a robust study of professionals' views of the use of video-EEG for diagnosis, neurologists perceived the technique as more accurate than psychiatrists.²⁹ In two cross-sectional studies, professionals also differed in their opinion regarding the use of symptom provocative procedures for diagnosis. Those physicians who used the procedure were more likely to regard the technique as useful and acceptable to patients,²⁴ whereas those who did not viewed it as unreliable and linked its use to ethical concerns.^{24,25} However, these studies had significant limitations and may not reflect current opinion due to the year of publication. A rigorous study of general and emergency physicians found that 62% reported confidence diagnosing PNES based on observation and only a minority (42-44%) were confident diagnosing PNES based solely on clinical history or symptom provocation.³⁵

In an internet survey of a broad group of health professionals, the majority reported using detailed explanation during diagnosis.³⁸ In a similar survey, health professionals reported the importance of spending time with patients to discuss diagnosis and treatment needs.³⁴ A robust interview study reported that some of the twelve patients with PNES perceived having unresolved questions post-diagnosis and difficulties understanding information they had been given.⁴⁸ Patients' negative experiences of diagnosis in one interview study were linked to feeling excluded from the diagnosis, as their own understanding was not sought.⁴⁵ In a separate interview study, PNES patients described positive experiences of diagnosis when the neurologist showed interest in them and was open to questions.⁴⁴ However, patients' reactions to the delivery of the diagnosis varied, with the former study reporting that patients reacted negatively to being "categorically" told they had PNES,⁴⁵ but the latter reporting that the certainty with which the diagnosis was delivered contributed to them appraising the diagnosis as correct.⁴⁴ Both studies were limited by their samples, however, with one recruiting a solely female sample and the other including patients with co-morbid epilepsy. One study found that a formal communication strategy for delivering the diagnosis of PNES was perceived by patients as highly acceptable and accessible; the minority who disliked the strategy cited its lack of relevance and unanswered questions as reasons for dissatisfaction.³⁷

Reaction to diagnosis

Variation in patients' reaction to the diagnosis of PNES was evident. Common emotional reactions were confusion,^{30,37,44} anger,^{26,27,30,37,44,45} anxiety,^{27,37,45} feeling blamed,⁴⁵ happiness,^{27,37,44,45} relief,^{26,27,30,37,44,45} upset/sadness,^{27,37} embarrassment,⁴⁵ and validation.^{37,44} One study identified that there were no gender differences with regards to patient's reactions to their diagnosis of PNES.³² In the same study, carers of men were reportedly three times more likely to reject the diagnosis than carers of women, although carers' perspectives did not appear to have been sought directly.

In one study, patients' anger at the diagnosis was associated with previous misdiagnosis of epilepsy and a subsequent lower confidence in the PNES diagnosis.³⁰ Where patients reported relief at the diagnosis this was related to confirmation of not

having epilepsy or brain damage^{30,44} and a perceived removal of responsibility.⁴⁴ The latter was inconsistent with a second interview study, however, where patients experienced the diagnosis as a transfer of responsibility from the professional to the patient.⁴⁵ Compared to the experience of relief,³⁰ angry reactions to the diagnosis were associated with seizure continuation; this link was not supported by an earlier study, however.²⁶

Acceptance of the diagnosis

One high quality study found that 72% of general physicians perceived that PNES patients do not accept their diagnosis.³⁵ When reviewing the perspectives of PNES patients themselves, however, several studies have found that the majority accept their diagnosis.^{26,30,32,43} Difficulties identified with patients accepting the diagnosis included: doubts about the diagnosis;^{44,48} being uncertain how it applied to their lives;^{43,44} challenges to their self identity;⁴⁵ and the psychological nature of the diagnosis.⁴⁸ One interview study reported that five patients out of the twelve interviewed continued to have doubts even following a psychoeducational intervention designed to improve acceptance of their diagnosis.⁴⁸ In two cross sectional studies, a small but significant number of GPs (12% and 35%) reported doubting the diagnosis,^{30,33} and this was linked to them maintaining PNES patients on anti-epileptic drugs.³⁰ In two interview studies, continued medication was linked to patients' own doubts regarding the PNES diagnosis.^{44,48}

In terms of outcomes, a retrospective study reported that patients with seizure reduction or cessation were more likely to have believed the diagnosis, although an average delay of 18 months between diagnosis and participation in the study is likely to have impacted on the reliability of participants' recall in this case.²⁶ Non-acceptance of the PNES diagnosis was considered a barrier to treatment in one robust interview study of patients' perspectives on intervention.⁴⁸

Theme 3: Perspectives of management and treatment issues

Management by Providers

Across two interview studies, patients with PNES described feeling abandoned by services to cope by themselves^{44,45} and reported a desire for support during their wait for treatment.⁴⁴ In two internet surveys, a broad range of professionals perceived their role as not ending post-diagnosis and perceived follow-ups as important.^{34,38} A cross-sectional questionnaire study identified that there were differences in professionals' perceptions of which service they felt was most appropriate to follow up patients with PNES, with psychiatry the greatest supported overall.⁴² A survey of GPs found considerable variation in who they considered most appropriate to follow up patients, with the most popular choice (30%) being themselves.³³ In a survey of health professionals, factors perceived as important determinants of whether PNES patients follow through with referrals to psychology/psychiatry were: discussion of diagnosis and treatment; neurologist follow ups; and spending time with the patient and family.³⁴ In three surveys, physicians who weren't specialists in neurology reported moderate levels of confidence in dealing with PNES patients.^{33,35,42} Within these studies, GPs reported feeling uncomfortable making the initial referral to psychology³³ and non-neurologist physicians (including family, internal and emergency medicine) deferred treatment decisions to other professionals.³⁵

Differences in opinion were evident in relation to driving restrictions recommended for PNES patients. Three studies found that the majority of physicians endorsed restrictions similar to those applied for epilepsy patients,^{28,35,39} whereas two others found that neurologists supported an individualised approach to restrictions.^{36,42} However, these results need to be interpreted with caution as four of these studies were limited by potential bias either due to recruitment strategy or low response rate.

Treatment Needs and Approaches

No studies have directly explored patients' preferences for treatment approaches for PNES, although studies have reported the potential treatment needs of patients. In two qualitative studies, patients described a need for more understanding and information.^{44,48} In a further interview study, patients with PNES described needing to

meet others with the condition to increase understanding and coping.⁴⁵ One small interview study reported that patients' understanding of their illness defined their expectations of therapy, with those who had a more psychological understanding tending to have greater expectations of therapy.⁴⁷ This was supported in a further qualitative study, where patients who described accepting their diagnosis had a greater understanding of the rationale for therapy.⁴⁴

The preferred treatment for PNES was psychotherapy in three studies with a broad group of professionals.^{34,35,38} A survey of neurologists and psychiatrists reported that the most appropriate treatment depended on the patient's psychiatric diagnosis; however psychotherapy was the preferred named approach.²⁹ In a cross-sectional study, psychology or psychiatry intervention was only deemed beneficial by a minority of GPs (35%), although inclusion of patients with co-morbid epilepsy in this study may have confounded these results.³³ In terms of barriers to treatment, there was inter-professional agreement in a survey study that the patient's own psychopathology was most likely to interfere with treatment,²⁹ which was consistent with an interview study of psychotherapists who perceived that the presence of co-morbidity would be likely to extend therapy.⁴⁶

There was agreement amongst neurologists and psychiatrists that 'doctors making mistakes' was also an important barrier to treatment.²⁹ A survey study with professionals identified that lack of availability of clinicians with expertise in PNES had a significant impact on treatment compliance.³⁴ In a large internet survey study, a broad group of professionals reported being unaware of different treatment options for PNES and supported the development of an evidence-based management pathway.³⁸ One high quality interview study explored therapists' views of the treatment needs of patients based on their experiences of providing therapy. Therapists reported that, for PNES patients with no history of trauma, interventions were short-term focusing on empowerment and stress management. For patients whose PNES occurred in the context of interpersonal trauma and longstanding

difficulties, therapists agreed that a safe therapeutic relationship, where the function of PNES could be understood and skills developed, was needed.⁴⁶

Relationship between patient and provider

Across several interview studies, PNES patients reported a number of difficult experiences with professionals including: repeated treatment disappointments;⁴⁷ communication difficulties;⁴³ lack of interest and neglect;⁴⁷ and feelings of being a ‘fraud’ and doubted.^{43,44} In a small interview study, patients with PNES who were more assertive perceived having their expectations met by professionals, whereas those who were more passive had more dissatisfying treatment experiences.⁴⁷ In the same study, patients with PNES described wanting professionals who were communicative and listened to them.

Treatment experiences

PNES patients’ experiences of treatment seem to vary considerably. Patients who received a psychoeducational intervention reported that it either increased their understanding of the link between emotions and their seizures, or was insufficient and left them with unanswered questions.⁴⁸ In one quantitative study, views about therapy varied between patients.³⁰ Therapy failure was linked to patients’ reports of a poor therapeutic relationship, resistance to “delving” and brief involvement. In contrast, others perceived benefits from therapy such as relaxation and time to discuss problems. An interview study with patients identified obtaining resources, involvement from professionals and not feeling alone as benefits from a psychoeducational intervention.⁴⁸ A small interview study summarised that feelings of disinterest, disregard and neglect by professionals tended to be barriers to treatment for patients with PNES.⁴⁷ Treatment experiences could also be challenging for professionals, with one in-depth interview study reporting that therapists felt poorly prepared to treat complex trauma in PNES patients, which in turn caused them confusion and uncertainty.⁴⁶

Discussion

This paper presents a narrative synthesis of research into stakeholders' perspectives on PNES. Considering the chronicity and severity of PNES^{50,51} it is surprising that not as much emphasis has been placed on understanding stakeholder perspectives in this area as it has in other areas of chronic illness.⁵² Perspectives research has also developed in relation to the broader area of somatoform disorders^{53, 54} but is under-represented in relation to PNES or to conversion disorders more generally.

This paper highlights strong evidence across several areas of the review indicating that patients with PNES vary widely in their perceptions of their condition, their diagnosis, and treatment. This is understandable given the heterogeneous nature of PNES, but has clinical implications in terms of providing services that meet patients' needs. Universal treatment approaches, such as those included in the review, are important developments within the field of PNES and are economically resourceful. However, these treatments may have limited benefits in such a diverse group and further research is needed to understand how such interventions can be tailored to most effectively meet the needs of these patients. Individualised interventions may be better suited for some patients and this approach for treatment, namely psychotherapy, was supported by most professionals in this review. This perspective reflects the opinions of the research community¹⁶ and psychological therapy is the area in which the current evidence base for PNES is being developed.^{55,56} However, patients' preferences of treatment approaches were not captured by the studies in this review and there is a pressing need for research into this topic. The advantages of developing services that incorporate patient preferences are that they may be more acceptable and relevant to patients.⁵⁷

A key theme, strongly supported by research evidence across the different aspects of PNES reviewed, is a collective uncertainty amongst patients and professionals. Patients felt uncertain and confused about their condition and a similar finding was identified in a qualitative study of patients with a broad range of neurological medically unexplained symptoms.⁵⁸ This uncertainty may therefore capture a key

aspect of patients' experiences of having physical symptoms that do not have a medical basis. In this review, patients' confusion persisted despite interventions aimed at providing education about the condition, suggesting that, for some patients with PNES, a lack of understanding of the condition may not solely be attributable to a lack of information. One potential barrier in reaching an understanding of the condition may be patients' acceptance of the diagnosis. Although the review identified a link between understanding of the condition and acceptance, this was based on a limited number of studies and further research is needed to establish the nature of this link.

A link was also established in this review between acceptance of the diagnosis and patients' views of treatment. Patients who were accepting of the psychological basis of their condition reported a greater understanding of the rationale for therapy and higher expectations of therapy. Although this finding is based on only two small interview studies, it does suggest future targets for intervention. Therefore, for patients with PNES, increasing psychological understanding of the condition would seem an important treatment priority to engage them with a psychological treatment approach. This is particularly key for this group considering that nearly a quarter of patients with functional neurological symptoms, such as PNES, do not attend their psychotherapy appointments when referred⁵⁹ and such research may help to identify ways of increasing patients' readiness for therapeutic interventions.

It is understandable that patients find PNES difficult to understand considering the evidence from several high quality studies that professionals also report limited comprehension of the condition and how to manage it. Professionals have described patients with physical symptoms that lack an organic explanation as 'difficult to help'^{60,61} and this seems to be reflected in the perspectives of professionals in this review. Lack of confidence was most often reported by professionals who managed PNES less routinely, particularly primary care professionals, and lack of expertise was identified as having an impact on treatment compliance. Developing an evidence-based treatment pathway is one approach that may help support professionals to feel more confident managing the condition. The most recent evidence also points

towards a 'joined up' multi-disciplinary team approach as being most beneficial for this patient group^{1,62} and this would allow for increased training, supervision and consultation between professionals with differing levels of experience.

Although in this review professionals reported that their role did not end after diagnosis, there was high quality evidence suggesting that patients feel "abandoned" and in need of more support during this time. One way this could be addressed is through the formation of post-diagnostic groups and such groups have already been established as effective for patients.⁶³ A further impact of patients feeling neglected by services could potentially be a feeling of 'disenfranchisement', which one study (albeit limited by its sample size) identified as a barrier to treatment. Feelings of disengagement from services could potentially be remediated through increasing patients' involvement in the decision making process. This has been linked to patients feeling they have more ownership over referrals for treatment⁶⁴ and is acknowledged as a feature of good quality health care.⁶⁵

This review highlights a number of areas where difference of opinion occurs between patients and professionals. The first area of disagreement was in relation to suitable terms to describe PNES. Professionals tended to support terms, such as 'non-epileptic' and 'pseudoseizure', however patients viewed these as potentially offensive and preferred the labels 'stress' and 'functional'. Historically, the latter term was favoured by neurologists for symptoms that lacked a neurological basis⁶⁶ but preferences appear to have changed over time. This gap between patients' and professionals' preferences may be significant, since the use of terminology that patients deem offensive may impact on therapeutic alliances. Although the research in this area was of high quality, a limitation of the existing research is the absence of studies solely investigating the views of patients with PNES. This hampers the interpretation of the results in relation to this patient group and further research in this area may facilitate the development of a consensus amongst patients and professionals regarding terminology.

A further area within which perspectives between patients and professionals were found to differ was in relation to the 'legitimacy' of the condition. Patients with PNES reported feeling doubted and they believed that others perceived the condition as not 'genuine'. This is understandable given that some professional groups perceived PNES as being voluntarily induced or 'feigned', which contrasts markedly with patients' perceived lack of control over the condition. This has also been reported more widely in relation to professionals' views of patients experiencing conversion disorders,^{67, 68} despite the diagnostic criterion stating that symptoms are not intentionally produced.⁶⁹ Not feeling legitimate⁵⁸ or credible⁷⁰ has been reported by patients with other conditions where a medical cause for their symptoms could not be found and possibly reflects the wider perspective that "society does not readily give people permission to be ill in the absence of an 'accepted' abnormal pathology or physiology" (p. 1178).⁵⁸ One approach that professionals could employ to ensure patients feel 'credible' is through the use of communication guidelines stating that patients should be believed and that their symptoms are genuine.^{37,71,72} This review highlights that, despite the existence of such guidelines, this message is not always being successfully communicated to patients and this has the potential for patients to feel they are not 'being taken seriously'. Issues of legitimacy also have wider implications such as engaging with therapeutic approaches that emphasise taking control of seizures, such as CBT and PIT.^{73,74} This may be challenging for patients who have been exposed to the suggestion that their seizures are voluntary, due to concerns that gaining control may confirm that their seizures are not 'genuine'.

There were varying professional opinions in relation to different diagnostic techniques, however the research in this area was of mixed quality which limits the conclusions that can be drawn. Differences in opinion existed about the value of different diagnostic techniques despite video-EEG being considered by many as the gold standard for diagnosing PNES.¹³ Views about the reliability and ethics of symptom provocative techniques were limited as they represented the views of professionals over fifteen years ago, although reflections on current practices seem little different⁷⁵. It is interesting that a lack of professional consensus about diagnostic procedures

exists despite this area of PNES being relatively well researched.^{5, 75} The findings of the review suggests that patients may experience marked variation in the diagnostic process depending on the services they attend and more could be done to ensure that services are working more cohesively at a national level.

Limitations

Considering the influence that families can have on the development and maintenance of PNES^{76, 77} it is surprising that no published studies have directly explored the perspectives of this group and this should be addressed by future research studies. Very few studies considered how the general public perceive PNES and the views of people with PNES who were not accessing services were also not represented. Research involving the latter group, although likely difficult to recruit, may have particularly useful insights in terms of accessing services and barriers to treatment. Studies were biased towards newly diagnosed patients and more in-depth research is needed with patients who have lived with the condition for a number of years or with those who have experienced cessation of seizures. This group may have important reflections on recovery and potential barriers to this. Most of the research in this area focused on patients' views of different aspects of their condition and more research is needed into specific views of treatment and treatment needs.

This review is limited by the difficulties inherent in combining qualitative and quantitative evidence. This precludes the use of qualitative analysis techniques such as meta-synthesis, which is an increasingly popular technique for understanding perspectives and experiences. There were also a number of limitations identified in the quality of the data included in the review. Generally the qualitative studies in this area could be improved in future through increased reflexivity and increased reporting of the number of participants that support the results presented. The quantitative studies could be improved through the use of more robust measures of perspectives, widening and extending recruitment strategies and higher participation rates.

Conclusion

This review summarises strong research evidence that patients with PNES have markedly varied perspectives on different aspects of their condition that contribute to the challenge of developing health care services that meet patients' needs. Across the different aspects of PNES reviewed, there existed high quality evidence to support a collective uncertainty amongst professionals and patients regarding the condition, its diagnosis and management. A number of differences in opinion were found to exist between patients and professionals in the areas of terminology and issues of the 'genuineness' of the condition, however the evidence for these differences in opinion was less conclusive.

The key clinical implication of this review is that both patients and professionals are in need of more support with understanding and managing the condition. Services can be organised to provide this for patients and professionals through increasing post-diagnostic support, establishing treatment pathways and increasing multi-disciplinary team working. Research incorporating patient perspectives of their treatment and experiences of services may aid in professionals developing services that are more acceptable to patients. The review identified that research into perspectives of PNES stakeholders is increasing, however a number of areas remain neglected including studies involving families of patients with PNES, people with PNES who are not accessing services and people who have recovered from the condition.

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Understanding the perceived treatment needs of patients with Psychogenic Non-Epileptic Seizures

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Abstract

This study aimed to understand the perceived treatment needs of patients with PNES who are awaiting psychological treatment. Twelve semi-structured interviews were conducted and data from these were analysed inductively according to the principles of thematic analysis. Four key themes were identified: *return to normality*; *post-diagnostic limbo*; *uncertainty and apprehension about therapy*; and *need for validation*. The results indicate that patients with PNES had clear goals for their recovery and clear ideas about their treatment needs. However, following diagnosis, many participants felt caught in 'limbo' due to uncertainties about their condition and feelings of being unsupported in progressing forward with their recovery. This linked with participants feeling unsure whether psychological treatment would meet their needs and for some there was apprehension about the potential negative consequences of therapy. The clinical implications of the research are discussed and recommendations for future research are made.

Keywords: Psychogenic Non-Epileptic Seizures; Perspectives; Views; Treatment needs; Therapy; Psychology.

Introduction

Psychogenic non-epileptic seizures (PNES) are episodes of altered movement, emotion, sensation, or experience, which are superficially similar to epileptic seizures but without the associated electrical brain activity [1]. PNES are psychiatric phenomena that are classified as conversion disorders in the ICD-10 dissociative disorders [2] and DSM-IV somatoform disorders [3]. Estimates of the community prevalence of PNES vary between 2 and 33 per 100,000 [4]. PNES patients represent an estimated 9-50% of those seen in specialist services for epilepsy [5]. Obtaining an accurate diagnosis can take several years [6, 7], often resulting in patients undergoing unnecessary medical investigations and treatment that may have iatrogenic effects [8]. Delays also result in patients not receiving timely and appropriate psychological treatment [5, 9].

Due to the heterogeneity of PNES patients, aetiology is generally conceptualised through multi-factorial models that include both biological and psychosocial contributions [10-13], although a widely accepted theoretical model of PNES is lacking [12, 14]. Factors identified as being influential in the development and maintenance of PNES include: trauma [15-17], family dysfunction [11, 18, 19], personality factors [10, 20, 21], neurological abnormalities [22, 23], stressful life events [11, 24, 25], psychopathology [26-28], and avoidant coping styles [29, 30]. At present, there is limited knowledge about the most effective ways of managing and treating PNES [31]. The main approaches include: optimised diagnostic communication strategies [32, 33], psychoeducational interventions [34, 35], pharmacological interventions [36], cognitive-behavioural therapy [37], and psychodynamic interpersonal therapy [38]. Systematic reviews for PNES have found no evidence to support any particular psychological treatment [39, 40]. Nevertheless, psychological intervention is considered the treatment of choice by professionals who work with PNES [41, 42].

Gaining service user views is central to the development of patient-centred services [43] and these views can contribute to services becoming more 'needs led'. Other benefits of service user involvement include more effective care partnerships; increased understanding amongst professionals of the illness experience; increased

compliance with treatment and care plans; and empowering of patients [44]. One way these benefits can be realised is through an increased awareness of how patients perceive their treatment needs. To date, however, only a limited number of studies have focused on the perspectives of patients with PNES.

Most of the perspectives research in this area has focused on patients' reactions to their diagnosis. Studies indicate that most patients agree with their diagnosis [34, 45-47], despite professionals' perceptions to the contrary [48]. However, patient doubts about their diagnosis are still common and typically pertain to how accurately the diagnosis relates to their experiences [46, 49], how it challenges their self identity [50] and the psychological nature of the diagnosis [34]. Patients' reactions to their diagnosis are varied. Some patients meet their diagnosis with positive feelings [32, 45, 49-52]; for others, however, diagnosis triggers a number of distressing and difficult emotional reactions [32, 45, 49-52]. Further common themes that exist throughout these studies are patients' perceived lack of control over the seizures [32, 46, 49] and difficulties understanding their condition [32, 34, 46, 49, 50, 52]. PNES patients also describe significant impairments in their lives as a result of the condition [34, 49, 52] and feelings of isolation and loneliness are commonplace [46, 49, 52, 53]. Patients with PNES also report feeling uncertain about recovery and optimism for the future varies widely [46, 51].

With regards to treatment needs, patients in two qualitative studies have discussed a need for more understanding and information about their condition [34, 49]. It has been reported that those patients with PNES who identify with a psychological understanding of their condition tend to have a better understanding of the rationale for therapy [49, 53]. Patients with PNES vary in their experience of therapy, with some seeing benefits in learning relaxation techniques and having the time to discuss problems, and others perceiving therapy to be a 'failure' due to brief involvement, resistance to 'delving' and difficulties in the therapeutic relationship [34, 52]. To date, there have been no detailed studies describing patients' perceptions of their treatment needs and expectations prior to commencing psychological treatment. This

study aims to fill this gap by capturing patients' perspectives on their treatment needs and expectations of forthcoming treatment. Patients' expectancies of therapy have been established as an important non-specific therapeutic factor [54, 55] and are defined as "...anticipatory beliefs the clients bring to treatment... [that] encompass beliefs about procedures, outcomes, therapists, or any other facet of the intervention and it's delivery." [56; p. 155]. Expectancies research has focused on understanding these factors and how they may shape the process and outcome of therapy. Research indicates that those who have positive outcome expectations of therapy tend to have better therapeutic alliances and outcomes [54]. Understanding therapy expectations may be particularly important for patients with PNES given research has shown that a quarter of patients with functional neurological symptoms do not attend their first appointment for psychological therapy [57].

The aim of this qualitative study was to gain an in-depth and contextual (incorporating broader influences on specific views) understanding of the perspectives of patients with PNES regarding psychological treatment for their condition, to inform the future management and treatment of this neglected patient group.

Methods

A qualitative methodology was chosen as most appropriate due to the exploratory nature of the study. Semi-structured interviews were chosen as the most appropriate method for gaining an in-depth understanding of PNES patients' perspectives. The data collection and analysis followed an inductive and interpretive approach informed by principles of thematic analysis [58, 59]. Although the overall aim of this study was not to construct a theory, there was an aim to understand the processes underlying the perspectives of participants. Thematic analysis conducted in this way can share similarities with Grounded Theory [60].

The interviewer was a female in her late twenties undergoing doctoral training in Clinical Psychology. Although she initially had little experience working clinically with patients experiencing PNES, she was experienced in neuropsychology and later in the

research process commenced a clinical role with this patient group. Due to her ongoing training in psychology she acknowledged that she held a strong 'insider's perspective' and remained aware of this throughout the research process through the use of the reflective diary.

Recruitment and Sampling

Purposive sampling was used to identify participants with PNES awaiting treatment. Participants were recruited from a PNES treatment waiting list within a National Health Service (NHS) Department of Clinical Neuropsychology within the North West of England. Ethical approval for this study was gained from the NHS Local Research Ethics Committee (appendix 6) and the research was approved by the Research and Development department for the recruiting NHS trust (appendix 7). Patients with PNES awaiting treatment who met inclusion criteria for the study were approached regarding participation between August 2011 and January 2012. Patients were eligible to take part if they were aged ≥ 16 years and had received a diagnosis of PNES that had been confirmed by a neurologist in the preceding twelve months. Basis for exclusion included: receiving a diagnosis over twelve months prior to recruitment; co-morbid epilepsy; and severe communication difficulties or severe learning disability. Patients who had already received psychological therapy for their PNES in the preceding 12 months were also excluded given the focus of the research being on patients' expectations prior to commencing psychological treatment for PNES. However, patients with past or current psychological involvement relating to other psychological difficulties were not excluded to ensure that the sample was representative of patients with PNES.

Potential participants were identified from the waiting list by an Assistant Psychologist within the recruiting service; those who met selection criteria were sent an information sheet (appendix 8) detailing the aims and nature of the research and a postal form to declare their interest in participating (appendix 9). Potential participants were also given the option of contacting the lead researcher (GF) to ask questions about the research or to opt-in directly. Upon confirmation of their interest

in the study, meetings were arranged with potential participants and a demographics questionnaire (appendix 10) was sent to be completed prior to the meeting. Participants were paid £10 for their participation to cover their time and costs.

Data Collection

Interview Procedures

Interviews were arranged either at the neuropsychology department or at the participant's home depending on their preference. Written informed consent was gained from participants by the lead researcher (GF) prior to the interview taking place (appendix 11). All interviews were conducted individually to ensure confidentiality and to encourage openness in the interview. All interviews were digitally recorded and transcribed.

Interviews were semi-structured and followed an interview guide (appendix 12) that consisted of a small number of open ended questions followed by further prompts, which is a typical format for in-depth interviews [61]. The main areas of the interview guide were initially developed through discussion between the lead researcher (GF), an experienced PNES researcher and clinician (RB) and an experienced qualitative researcher (JF). The guide was further developed by the lead researcher and was informed by relevant treatment literature in PNES. Further feedback was gained from experienced researchers and clinicians in the NEST research group [62] to gain consensus on the guide. The guide covered four main areas pertaining to the participant's: understanding of their condition, their perceived treatment needs, their past treatment experiences and their expectations of psychology. The lead researcher formally reviewed the interview guide with the research team and collaborators following the second interview and adaptations to the interview guide were made on the basis of this feedback. The lead researcher also developed the interview guide iteratively in response to reflections on subsequent interviews.

Questionnaires

Prior to the interview, participants were asked to complete a demographics questionnaire. Following the interview, participants were asked to complete two

further questionnaires investigating common symptoms relating to psychopathology and trauma. The questionnaires were used to describe the sample and provide some context to the interview data.

Brief Symptom Inventory [63; appendix 13]

The Brief Symptom Inventory (BSI) is a 53 item questionnaire that assesses symptoms of psychological distress. The BSI has been established as having good reliability (subscale alphas ranging from .71 to .85 and test-retest coefficients ranging from .68 to .91) and the measure's convergent, construct and predictive validity have also been established [63]. Item responses are on a five point Likert scale ranging from 0 (not at all) to 4 (extremely), resulting in a Global Severity Index (GSI) score between 0 and 212. These scores are then converted to T-scores that can be interpreted in terms of their likely 'caseness'.

Trauma Symptom Checklist [64; appendix 14]

The Trauma Symptom Checklist (TSC) is a 40 item questionnaire that assesses symptoms of trauma and has been shown to be reliable (full scale alpha = .90, subscale alphas .62 to .77) and has good predictive validity [64]. There is further evidence to support the measure's convergent and discriminant validity [65]. This questionnaire was chosen as a proxy measure of trauma, rather than asking participants directly about potentially traumatic experiences. Item responses are on a four point Likert scale from 0 (never) to 3 (often), yielding total scores between 0 and 120. Standardisation of this measure resulted in totals of 20.9 (n = 2,072, SD 11) and 26.0 (n= 761, SD 12) for non-abused and sexually abused females respectively [64]. A further study, compared the scores of a clinical sample and a non-clinical sample which resulted in totals of 48.3 (n=72, SD 20.1) and 29.4 (n=138, SD 16.8) respectively [66].

Analysis

The analysis was informed by guidelines set out by Braun and Clarke [59] for inductive or 'data driven' thematic analysis. The initial stage of analysis involved the researcher immersing herself in the data through transcription and re-reading of the manuscripts. This was followed by open coding of the data (appendix 15), which involved working through interviews line by line and creating codes through a process of constant

comparison which involves “asking questions of the data; and the making of comparisons for similarities and differences between each incident, event and other instances of phenomena” [67, p. 74]. The researcher recorded memos during the ongoing analyses to capture developing ideas and hypotheses about the data. In line with the inductive nature of the research, analysis was carried out in parallel with ongoing data collection to inform this process further.

The process of organising the data into themes was conducted by sorting codes according to relationships identified between them. This resulted in the identification of a number of potential themes. The relationships between themes and between the different levels of themes were identified from the data to help develop initial thematic maps to test out potential thematic structures. Once an initial set of themes were identified they were reviewed through an iterative process of re-visiting the data and further refinement of codes. This process of analysis continued until a final set of themes was identified that were considered to represent a cohesive understanding of the data. This analysis then shaped the narrative of each theme and the main connections between the themes that tell the ‘overall story’ [59].

Reliability and validity

The researcher used guidelines for the conduct of good qualitative research to inform the research process [68, 69]. The use of a reflective diary helped the researcher consider her own personal thoughts and experiences of the research and the potential influence of these on further data collection. This reflective process helped to ensure transparency and reflexivity during the research. During the process of data collection, coded transcripts were discussed and reviewed with an experienced qualitative researcher (JF) to ensure credibility of the coding. The process of constant comparison aided in the identification of similarities and differences in the data, strengthening the validity of the analysis. Particular attention was also paid to instances of disconfirming data. At various stages of the analysis, themes were shared with the research team (JF & RB) who assisted in their ongoing refinement. A further check of the quality of the themes was carried out through consideration of whether they were internally meaningful and sufficiently distinct from one another [70]. To demonstrate the

validity of the data, illustrative quotes have been selected for the main points of the analysis.

Results

In total, 40 potential participants were contacted and 17 expressions of interest were received. Three patients were excluded, one due to time since diagnosis and two due to commencing psychological therapy for PNES. Another patient withdrew their consent prior to the research meeting. A further interview was completed but excluded from the analysis as it emerged that the participant had already commenced psychological therapy for PNES at the time of interview.

Twelve participant interviews were included in total. Checks of medical records confirmed that all participants had a diagnosis of PNES from a specialist neurologist that was informed by either video-electroencephalography (EEG), ambulatory EEG, or through observation of seizures. The twelve interviews lasted between 45 and 110 minutes. Full demographic details of the participants are detailed in Table 1.

Demographics

All participants at the time of interview were awaiting psychological therapy for PNES and they reported that this was the only treatment they had been offered since diagnosis. Three were continuing anti-epileptic medication and all others had either discontinued or had never taken medication for epilepsy. Nine women and three men took part in the study with ages ranging between 17 and 64 years. There was a wide range of illness experiences, with problem duration ranging from one to 35 years and typical seizure frequency rates varying from one seizure per month to 32 seizures per month. Eight of the twelve participants had past or ongoing experiences of therapy although only one of these was specific to PNES. Ten were above the cut-off for psychopathology 'caseness' on the BSI [64]. One person had a particularly low TSC score compared to norms, just below half of the sample's scores were broadly comparable to those reported for a clinical sample [66] and half scored extremely high on the trauma scores compared to published norms [64].

Table 1: Demographic and questionnaire characteristics of interview sample.

	Gender	Age (years)	Time since onset	Time since diagnosis	Seizures per month	Employment	Experience of therapy (with therapy focus)	TSC scores	BSI scores (GSI;*indicates caseness)
Participant 1	Female	17	5 years	4 months	10	Employed	Past (PNES)	32	65*
Participant 2	Female	56	18 years	4 months	7	Sick/Disabled	None	36	62
Participant 3	Male	30	4 years	5 months	1	Employed	None	60	≥ 80*
Participant 4	Female	34	1 year	3 months	9	Sick/Disabled	None	13	55
Participant 5	Male	59	9 years	10 months	3	Sick/Disabled	Ongoing (Non-PNES)	75	≥ 80*
Participant 6	Female	38	35 years	7 months	32	Sick/Disabled	Past (Non-PNES)	65	69*
Participant 7	Female	56	2 years	5 months	12	Sick/Disabled	None	59	75*
Participant 8	Female	28	9 years	4 months	1	Employed	Past (Non-PNES)	38	64*
Participant 9	Male	64	12 years	4 months	7	Sick/Disabled	Past (Non-PNES)	44	77*
Participant 10	Female	59	8 years	3 months	10	Sick/Disabled	Past (Non-PNES)	46	69*
Participant 11	Female	49	1 year	8 months	4	Sick/Disabled	Ongoing (Non-PNES)	54	76*
Participant 12	Female	35	5 years	4 months	3	Employed	Past (Non-PNES)	56	71*

Results of Thematic Analysis

As a result of the thematic analysis, four key themes were identified: *return to normality*; *post-diagnostic limbo*; *uncertainty and apprehension about therapy*; and *need for validation*. Figure 1 illustrates the main connections between the themes.

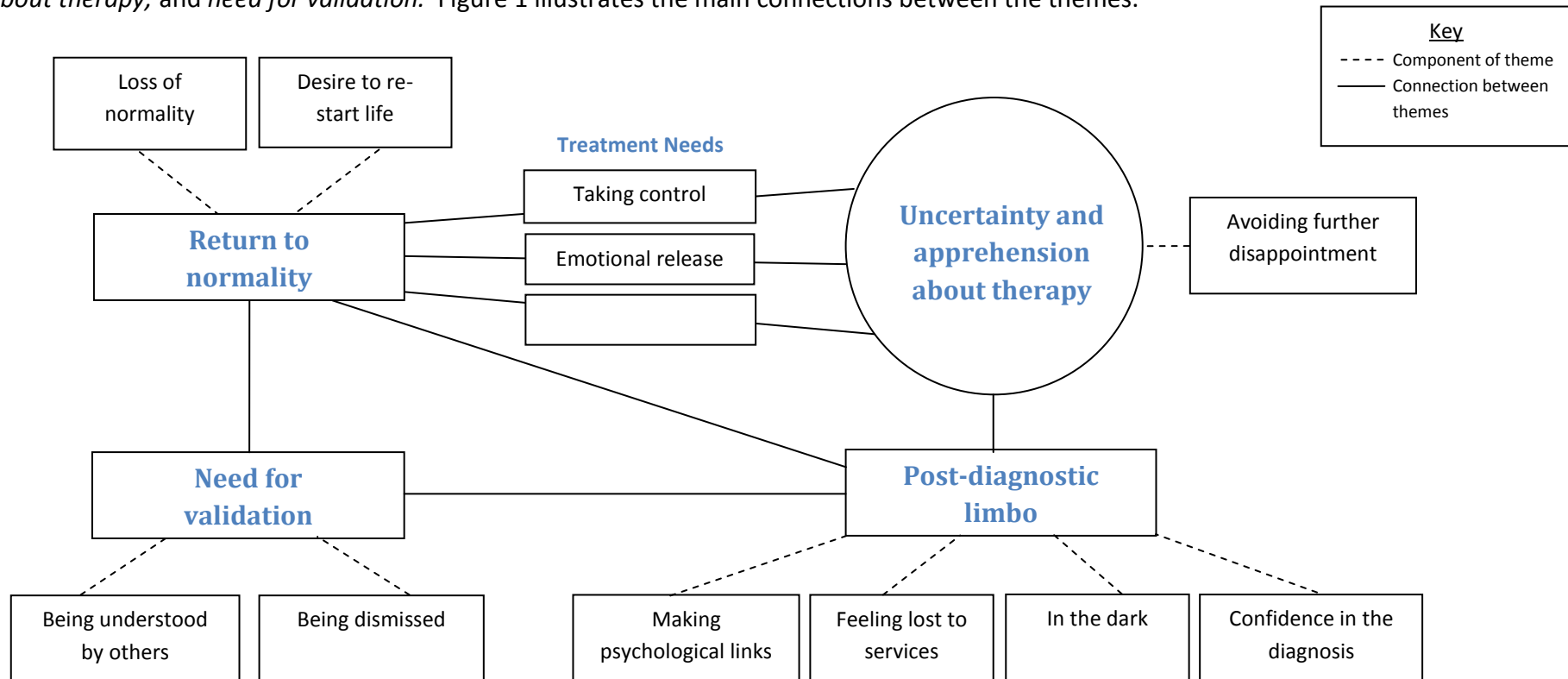


Figure 1: Diagrammatic representation of the results of the thematic analysis.

Theme 1: Return to Normality

A key influence on participants' perceived treatment needs was their goal of 'returning to normality'. Becoming 'seizure free' was the ideal for most and 'regaining life' was perceived to be a valuable consequence of this. The perceived likelihood for achieving recovery varied, with common perceptions of there being 'no guarantees' and uncertainty about prognosis; typically arising from feeling in the dark about the condition (discussed further in theme 2). Some questioned whether they were 'stuck' with their condition, which linked to beliefs in an organic or physical cause for their seizures.

"I think I was born like that and it's gonna stay like that." –

Participant 11.

Those who attributed the cause of their condition to more psychological factors were in general more hopeful of the possibility of change.

Subtheme 1.1: Loss of normality

'Loss of normality' captures the many ways participants perceived themselves and their lives as different due to the seizures.

"Why- why have I gone from being... normal to not" – Participant 4.

Participants described that experiencing seizures set them apart from others and resulted in feeling 'not normal'.

"Well hang on why am I doing that and you're not? [] So I feel the odd one out." – Participant 1.

Typical family life was disrupted, with perceptions that seizures caused significant stress and burden on others. Some described their families feeling 'helpless' and 'punished' and consequently, feelings of self blame and guilt were commonly felt

about the impact of the condition on others. Some described experiencing 'role reversals' and gave accounts of feeling 'childlike' and 'babysat'.

"He even like, you know like you do with a child, 'don't walk on that side of the road,' he's at it, 'mum walk on this side of the road.' He's quite protective that way." – Participant 2.

Participants' lives were disrupted due to a number of impairments and losses linked to the seizures. Cognitive and physical impairments were experienced, including loss of vision, memory difficulties, co-ordination and acute periods of incapacity. Feelings of loss spanned valued work roles, pursuits and aspects of the person's self image, such as confidence and self reliance.

"I don't feel safe going out on me bike which I used to. And I don't see anyone 'cause I'm at home. I've lost two jobs because of it, so I can't work, no one'll employ me. Can't even go and do voluntary work." – Participant 6.

Sadness and a sense of 'being on the scrapheap' were often discussed as a consequence of losses. Loss of autonomy and independence were also prevalent consequences of the condition and a more restrictive lifestyle was linked to participants' perceptions of being vulnerable. Restrictions were sometimes described as being imposed by others, particularly when there was a high level of family concern. Some participants were unable to work, drive or carry out pursuits as a result of being viewed as a 'risk' by others, often resulting in frustration.

"My mind's willing and my body's willing but people say no." – Participant 10.

Emotional wellbeing was also described as being impaired by the condition and this was equally reflected in the self reported measures of distress. Some participants felt

anger and a sense of 'unfairness'; for most, the seizures caused significant anxiety and worry. Depression and feelings of hopelessness were also identified but less frequently.

Subtheme 1.2 Desire to re-start life

Gaining control of seizures was perceived by participants as an opportunity to move forward with their lives, which they viewed as on hold and 'stuck'.

"Ah, it would be like re-starting my life again." – Participant 7.

Re-starting life for some was about regaining past losses such as: fulfilling roles again; achieving physical health; gaining independence; and enjoying life in a way that was described as difficult whilst experiencing seizures.

"It's another thing that's delaying me getting back into, into a routine of life, you know, where I enjoy life, I can smile and, you know what I mean, I can do things and, you know what I mean, and get about like." – Participant 5.

Theme 2: Post-diagnostic limbo

Arising from their desire to 'return to normality' participants had sought help from medical services regarding their seizures, which had resulted in their diagnosis of PNES. Participants felt they had been left with a number of 'unknowns', uncertainties and, for some, doubts following their diagnosis that left them feeling 'in limbo'. For most this was described as a distressing and worrying place to be.

"I feel I've been left in limbo." – Participant 6.

Limited understanding and lack of certainty about the diagnosis (subtheme 2.1-2.3) resulted in patients adopting a tentative stance to their agreement with the diagnosis.

"I've come away accepting it, that it could be that." – Participant 2.

'Post diagnostic limbo' also captured a sense of being 'abandoned' by services (subtheme 2.4).

Subtheme 2.1: In the dark

Following diagnosis, participants described feeling 'in the dark' about their condition. One participant had an understanding of the condition prior to diagnosis due to a personal interest in neurology; for all others, however, PNES represented an 'unknown' condition.

"I couldn't get my head round it, I couldn't understand, because I've never heard of anything like that." – Participant 7.

The unknown nature of the condition was most often linked to feelings of shock and confusion about the diagnosis and there was a perception that the condition also represented something of an enigma for professionals also.

"It's an unknown thing really in the, in the way of the medical situation like, sort of thing, it hasn't been quite got to grips of by the medical profession yet." – Participant 5.

For some, the diagnosis raised more questions than it answered and the value of the diagnosis was referred to by some as 'meaningless' and a 'blanket diagnosis'.

"That's where people get stuck because so many people are so different with it, yeah it's almost a blanket diagnosis." – Participant 12.

However, for a limited few, the diagnosis did provide some answers and facilitated a further search for information, such as over the internet, although these participants still viewed their knowledge as limited.

Information provided during the diagnosis was sometimes viewed as difficult to make sense of and participants also reported receiving conflicting information about their diagnosis. Some participants discussed professional 'jargon' as a barrier to understanding.

"They tell you but it's all doctory, I don't really know what they're saying." – Participant 8.

For some participants, the power imbalance they felt in the consultation prevented them from questioning professionals further.

Subtheme 2.2: Confidence in the diagnosis

Participants' uncertainty was often due to a lack of confidence in the diagnosis. The diagnosis was sometimes perceived as a judgment or opinion of the neurologist's, and this was communicated by participants through phrases such as 'he thinks...' and 'in his opinion...'. Some discussed issues about the potential reliability of the diagnosis, with one participant describing being unsure if their diagnosis was based on a 'typical seizure' and another questioning whether professionals would have reached the same diagnosis if it had been made at an earlier date. For one individual, confidence in the diagnosis resulted from the immediacy with which the condition was recognised by her neurologist; for others, however, the 'quickness' of the diagnosis was distressing.

Where participants had a previous diagnosis, lack of confidence in the new diagnosis resulted in them being in a diagnostic 'no man's land', uncertain of what to believe. Experience of past misdiagnosis seemed to influence participants' perceptions that the diagnosis was not static and may change again.

"In two or three years time they might tell me it's a different one." – Participant 2.

Subtheme 2.3: Making psychological links

An important theme regarding participants' certainty of their diagnosis was the psychological nature of the condition. Initial reactions to being diagnosed with a psychological condition were concerns about sanity and 'losing their mind'.

"I thought I was going mad when they first mentioned it. I said to him, 'am I going mad?'" – Participant 7.

Most participants had not made psychological links prior to their diagnosis and were uncertain as to how psychological factors identified or explained during the diagnostic process were relevant to them. For some the psychological nature of the condition was hard to make sense of because it did not fit their image of being 'carefree' or they were unable to identify past difficulties or traumas that they could attribute the condition to.

"So I can't make a correlation between that side of it... because there's nothing that's happened- that's caused damage, psychological damage or anything like that, that'd cause this to happen as a result." – Participant 4.

However, these reports of being 'carefree' or having no past difficulties were not always in line with self reported measures of distress and trauma.

The psychological explanation of the condition was also challenging for those with the existing belief of a physical cause for their illness, with these beliefs continuing for some despite the diagnosis. Although not all participants identified with a psychological explanation for their seizures, they all discussed an openness to consider a psychological explanation. However, those with a greater understanding and identification with psychological causes of their condition were more able to acknowledge the potential role that psychology could have in their future treatment (discussed further in theme 3).

For some individuals, the lack of a definite psychological explanation resulted in an ‘internal’ search for answers, which involved considering past life events and attempts to identify triggers and patterns. One participant was actively trying to find their own answers so they could avoid going to psychology.

“I’m trying to find the answer meself, so I can stop it meself, so that I don’t actually have to go and see a psychologist.” – Participant 3.

Some participants had made links with psychological triggers either prior to diagnosis or as a result of the consultation. The diagnosis seemed more relevant for these participants, although they still wished to understand the psychological links in more depth.

“I had like the breakdown, I was depressed a lot and I was thinking a lot... It may have been the time that my brain just gave up kind of thing... I don’t know. I mean I suppose I won’t know until I’ve had my- my psychology. Tell them my experiences and they’ll know whether they are linked or not.” – Participant 8.

The main narratives discussed related to emotional triggers, either through a ‘build up’ of emotions or through past difficulties impacting on the present. A ‘build up’ of emotions, particularly anxiety, was perceived to result in seizures when participants felt overwhelmed.

“I think everything just gets overloaded. It’s an overload. And that’s the trigger and the body just- It’s the body’s way of coping and releasing it I think.” – Participant 12.

For some, these overwhelming emotions were due to psychosocial difficulties such as relationship problems, separations, financial concerns and occupational difficulties. Emotional triggers were also discussed in relation to distress caused by ‘reliving’ past experiences through nightmares and intrusive images.

“You’ve got to learn to move on from things. So, in one way I have, in another way I haven’t, because, uhh... I do still have nightmares [] So although you don’t think things are there in your mind... possibly are, aren’t they?” – Participant 2.

This was despite participants reported attempts to ‘bury’, ‘suppress’ and ‘move on’ from past difficulties and self reported trauma symptoms for these participants were found to be high.

Subtheme 2.4: Feeling lost to services

An important aspect of being ‘in limbo’ was participants feeling left or ‘abandoned’ by professionals, resulting in feelings of being alone. Lack of post-diagnostic support and lack of contact from the psychology service during their wait (which averaged several months) accentuated these feelings.

“It’s a long time to be on your own not knowing what’s going on. You just wish there was somebody there you know.” – Participant 7.

Most described a lack of recommendations or a plan following their diagnosis, resulting in participants feeling uncertain of the way forward and feelings of helplessness and frustration that recovery was at a ‘halt’. For some this created feelings of desperation for their forthcoming psychological treatment.

Theme 3: Uncertainty and apprehension about therapy

Participants had very certain ideas about what they wanted to gain from attending therapy. These perceived treatment needs were: taking control; gaining an emotional release and finding answers. However, there was uncertainty over whether psychology would meet these needs and for some, the prospect and process of addressing these needs resulted in feelings of apprehension about therapy (discussed further in subthemes 3.1-3.3). Uncertainty and apprehension about therapy was also influenced by past difficult experiences with services (subtheme 3.4).

Underlying the uncertainty and apprehension about therapy was a more general sense that participants were unsure what to expect from therapy.

“Because if I can’t find it, how are they gonna do it? So it’s quite scary. Umm... But at the same time, a little bit exciting. I suppose. In some respects. [] It could be that... I actually get loads out of it and I find it the most exhilarating experience ever and I turn into a better person for it. That’d be great. But I just got this sensation it’s gonna be a horrible time. Maybe it’s not, maybe I’m wrong.” – Participant 3.

This was linked by some to a lack of understanding and information about psychology with only one person being aware of a specific psychological intervention.

“They can’t wave a magic wand and say there you go it’s gone now, you know. You know what these- what do these people do? What do these people do?” – Participant 7.

Whether therapy would be of benefit was questioned, but an outlook of having ‘nothing to lose’ and being ‘willing to give it a try’ resulted in some patients ‘going along’ with therapy despite uncertainties and reservations. For some this was linked to desperation for change and feeling there was no other option.

“Well that’s all that’s on offer, there’s nothing else on offer.” – Participant 7.

For others, there was a sense that psychology was a ‘low risk strategy’ and they attempted to resolve their apprehension by anticipating that they would disengage if it wasn’t beneficial or they didn’t like it.

“Well, I don’t think it’s going to do any harm.” – Participant 9.

However the apprehension of therapy resulted in some describing a feeling of wanting to 'get it over with' and for some this resulted in avoidance of thinking about the upcoming appointment.

"It's not something I'm thinking about because I don't want to get stressed about going there when I don't have to yet." – Participant 12.

Subtheme 3.1: Finding answers

One of the main treatment needs discussed by participants was 'finding answers', due to a perceived lack of understanding about the condition. 'Finding answers' meant something different to each participant but typically related to understanding triggers and causes of the condition and resolving their uncertainties about the diagnosis. For some, understanding impairments relating to the seizures, such as memory difficulties, was a priority. One participant was keen to get an answer to whether he could drive again. The perceived benefits of finding answers related to reducing distress by making the 'unknown known' and increasing the ability to cope by understanding the problem.

"You can't battle the unknown." – Participant 3.

Participants hoped their need for clarity and knowledge would be met by the psychologist and that their 'unanswered questions' may be resolved. For some this was linked to the hope that the psychologist would be an 'expert' and 'know where to look'. Despite these hopes, there was uncertainty whether they would get the answers they desired. This was due to participants questioning whether the psychologist would know the answer or whether they may miss the answer. One participant questioned whether the psychologist could find an answer he couldn't. For others there was a sense that maybe no-one could answer their questions due to the condition not being understandable.

“Maybe there’s not meant to be a sense of it. Maybe it is just one of them things that happens and then you just get on with it.” – Participant 6.

Some participants had feelings of apprehension toward the answers they might hear and what they may learn about themselves. For some this was a concern that the answers would confirm personal responsibility for the seizures; for others, it was a difficult prospect that their seizures might relate to a past trauma they hoped they had moved on from.

Subtheme 3.2: Emotional release

As discussed previously, participants identified that they had a tendency to ‘bottle up’ their feelings. Therapy was therefore discussed as a place to get an ‘emotional release’ and to ‘vent’.

“Be nice to get a lot of things off my chest; that I don’t wanna keep bottling up.” – Participant 1.

Although participants often acknowledged significant others as sources of support they also reported difficulties and reluctance about opening up to them. This was due to concerns of burdening others, feeling dismissed by them and participants wanting to maintain an image of coping. There were hopes that the psychologist would therefore be a ‘confidante’, who they could open up to in ways they didn’t feel comfortable with others. Therefore, participants discussed the importance of the psychologist being someone they felt comfortable to talk with.

“It has to be somebody that I’d be willing to sit down and have a coffee with.” – Participant 12.

For those who saw this as important, they anticipated that it would be difficult or potentially disengaging if the psychologist was not the person they hoped for.

Although participants acknowledged the potential benefits of opening up, they also expressed significant concerns, particularly regarding talking about past difficulties.

“Some things are best left unsaid and left alone.” – Participant 6.

Participants were apprehensive that they would have to relive traumas and potentially be overwhelmed by emotions.

“I feel sick when I mention it. [] ‘Cause you just don’t wanna relive all that again. You- you don’t even want to think that you’ve put up with all that either.” – Participant 2.

There was also apprehension about therapy being too revealing, with psychologists being described as ‘brain diggers’ or people who ‘delve’ and this was often the perspective of those who had experienced past traumas. For one person, there was a concern about uncovering an unknown ‘deep seated issue’ and this may be understandable given he scored highly for symptoms of trauma.

“It’d mean [having many sessions] that they, you know, through speaking to me, somebody had found this real big deep seated issue. [] Once they start unwrapping the layers, what else are they gonna find? [] I don’t want them to keep digging. I want them to find the problem and then just stop.” – Participant 3.

Subtheme 3.3: Taking control

An important treatment need for participants was taking control of their seizures, ideally resulting in the seizures stopping or having less of an effect on them. Participants were unsure if this need would be met by psychology. Need for control seemed to arise from feeling out of control. Participants’ seizure experiences were described as physical losses of control, captured in descriptions of being ‘powerless’

and ‘incapacitated’. Participants represented the seizures as ‘beyond their control’, with unpredictability and feeling ‘trapped’ by the condition being important concepts.

“That’s where it changes your life, because... your life’s controlled.” –

Participant 2.

Loss of control was felt by participants following their diagnosis due to a lack of direction and certainty. There was also a broader sense of loss of control in relationships with professionals and participants described feeling excluded from their medical care and needing to comply with professionals.

Participants had different ideas about the ways they could take control of their condition and consequently ‘return to normality’. Those with continuing physical explanations or significant doubts about their diagnosis were more likely to perceive medication as useful in controlling seizures and were more uncertain about the potential for therapy to help with this. For some, this resulted in continuation of anti-epileptic medication.

“In my mind I think maybe they’re wrong and I think that’s why I can’t let all my tablets go in case I need them, it’s like back up.” – Participant 11.

Those with a greater psychological understanding of the condition had more of an expectation of the role that psychology could have in controlling their PNES. This was mainly related to identifying and managing triggers and learning strategies from the psychologist to gain control of their seizures.

Although gaining control was anticipated as a positive move forward, participants were also uncertain if this was attainable due to questions about whether the condition was treatable and uncertainties about prognosis (discussed in theme 1). Taking control was a difficult prospect for some due to the perceived inference that they were responsible for the seizures. This perception, that others viewed the seizures as volitional, also caused the participants’ distress.

Subtheme 3.4: Avoiding further disappointment

Participants discussed deliberately keeping their expectations for psychology limited and uncertain so as to avoid disappointments.

“I’m trying not to really, have too many expectations... if you build it up too much in your head, you’re only letting yourself down for a massive fall at the other end, so you might as well just... go along with the flow.” – Participant 4.

Keeping expectations uncertain was linked to past treatment disappointments. Past disappointments included treatment failures, misdiagnosis and dissatisfaction with services, which often continued to cause annoyance and distress for participants.

Those participants who had negative experiences of past therapy were apprehensive that their upcoming therapy would be similar, such as it not being worthwhile, aversive or too narrow in focus.

“Is it gonna be worth it or is it gonna be another waste of time?” - Participant 6.

Theme 4: Need for validation

Participants described a sense that their experiences were not only difficult for themselves to understand but also difficult for others to understand. There was discussion of the ‘legitimacy’ of their illness being questioned by others, sometimes resulting in them feeling blamed and that professionals had not taken them or their condition seriously (subtheme 4.1). For this reason, participants hoped to obtain validation from sources of support they identified as being most likely to understand them (subtheme 4.2).

Subtheme 4.1: Feeling dismissed

There were frequent reports of participants not feeling understood and being ‘dismissed’ by professionals and family. The ‘genuineness’ of the condition was a concern and comparisons were made between PNES and epilepsy, with the latter

being perceived as more known, better understood and more explainable. Some were concerned that others viewed them as a 'fraud' or that they were 'faking it' and therefore the reality of the illness for participants was denied.

"But you know you, you know you're suffering with something. But it's like they're saying "Well no you're not, go home, go and get on with it."" – Participant 6.

Some discussed feeling rejected and blamed by their family due to the condition. In some cases, awareness of how they might be viewed negatively or concern about other's negative reactions had resulted in embarrassment and avoidance of social situations. This heightened feelings they were different or not normal (as discussed in theme 1).

There was a perception that professionals had not tried to understand them, by not listening to them or taking their concerns seriously. This sometimes resulted in participants feeling angry towards professionals and 'disengaged' from services.

"It just reaches a point where you just think, actually you're not listening to a word I'm saying, so it doesn't matter. I could come into you and say, 'I turned blue last week and then I went purple.' And they'd go, 'oh really.' But they wouldn't take it on board, they wouldn't listen." – Participant 4.

However, feeling their voice was not heard was difficult for participants, particularly as this conflicted with feelings of being self aware or a 'self expert'.

"I think the only person that knows your body is you, you know your body better than anybody else." – Participant 11.

The importance of being taken seriously was also reflected in participants' descriptions of positive interactions with professionals as being when they were attentive to or validating of them.

Subtheme 4.2: Being understood by others

Gaining understanding from others was an important need for participants. Most perceived some form of post-diagnostic peer support as potentially beneficial. Those who had actively sought this support had found it reassuring and normalising. There was discussion of support via a group format.

"If there was a support group it's be a hell of a lot easier because you could relate to others who are suffering from the same problem. Umm. You wouldn't feel like you're an outcast." – Participant 7.

However this did not suit all participants, with one describing that discussing others' problems would not be beneficial as this would result in him avoiding his own.

For some, there was discussion of increasing systemic understanding of the condition. Participants thought this could be achieved through families being involved in support groups and therapy.

"I think that it might be helpful to include the other people as well because it's not just about you." – Participant 12.

For others there was a hope that, through their own experiences in therapy, the condition would be easier to explain to others and, consequently, they would be more understood.

Gaining support from the psychologist, for most participants, went beyond gaining answers and practical solutions. Despite uncertainty and apprehension about many aspects of therapy, one area participants seemed to be relatively certain about was

that the psychologist would make efforts to understand them and their experiences.

“Be nice to talk to somebody that actually understands me for once, how I feel. I mean, I know they’ve not gone through it themselves... but obviously they’ll have done a lot of research, else they wouldn’t be there talking to people like me.” – Participant 1.

Participants identified that they wanted the psychologist to be interested in them and get to know them as a person. There was a perception that the psychologist would be experienced in working with people with PNES and would provide some understanding about their experiences others had not been able to. For some, being understood was related to being believed and heard. One participant, however, felt the psychologist would not be interested in them and that they would be viewed as ‘another NHS number’, and attributed this to the psychologist’s status as a doctor.

Discussion

This is the first study to explicitly focus on the views and perspectives of patients with PNES, regarding their treatment needs and expectations of psychology. Four broad themes were identified that represented participants’ views, including: return to normality; post-diagnostic limbo; uncertainty and apprehension about therapy; and need for validation.

Theme 1: Return to normality.

The first theme, a ‘return to normality’ was a goal for recovery that all participants reported. Experiencing PNES had impacted on lives through: loss of role, loss of pursuits, loss of independence and impaired emotional wellbeing, which are all impairments and losses similar to those identified in previous studies of PNES [34, 49, 52]. Participants’ wished to ‘re-start their lives’ and being seizure free was the most frequently identified way of achieving this. The perception that cessation of seizures would be most beneficial for recovery is in line with research evidence which has identified that cessation, rather than mere reduction of seizures, is associated with

improved quality of life [71]. Participants' accounts of the distressing unpredictability of seizures may potentially offer an explanation for why cessation was the preferred outcome for most rather than just reduced frequency. This contrasts with treatment research on PNES, which typically uses seizure frequency as the primary outcome [37, 38]. This study suggests that, from a patient perspective, duration of seizure free periods or proportion of patients who are rendered seizure free may be more meaningful outcome measures. However, further research explicitly focusing on what would constitute a significant outcome for patients with PNES is clearly needed.

Furthermore, it seemed that a desire for 'normality' was linked to an awareness of being different or negatively perceived by others. Research into epilepsy has long established that experiencing seizures can result in patients feeling stigma due to having an 'undesired difference' and this has been linked to a reduced quality of life [72]. Patients in this study discussed isolating themselves due to the embarrassment caused by the seizures. This sense of shame may be understandable given that they reported fearing others' negative reactions and felt others did not understand their condition. This has been previously reported to be the experience of a broader range of patients with unexplained neurological symptoms who reported finding the condition as challenging to their social identity [73].

Theme 2: Post-diagnostic limbo

Theme 2 identified that PNES patients reported having a lack of understanding and certainty about their condition post-diagnosis. A lack of information and explanation was highlighted as influential in this, which is consistent with the findings of previous interview studies [34, 49, 50]. This is important considering effective communication of the diagnosis has been well established as one of the first steps in the practical management of PNES [74]. Evidence has shown that patients can be rendered seizure free through careful presentation of the diagnosis [75] and communication strategies have been developed to aid in the successful communication of the diagnosis [32, 33]. This study highlights the need for further effective interventions at earlier stages in treatment to help allay patients' distress linked with being 'in the dark'. Psycho-

educational groups [34, 35] are a promising development for tackling the ‘knowledge gap’ after diagnosis, although such generic interventions are clearly unable to address all areas where an individual’s understanding may be lacking. Despite the emergence of these interventions, it seems there was no access to these services for the participants in this study and this highlights potential disparity in service provision for these patients.

Another aspect of the theme of post diagnostic limbo was patients’ perceptions of a distressing lack of post-diagnostic support, which some experienced as being ‘abandoned by services’. A perception of being marginalised by services has been reported previously by patients with neurological medically unexplained symptoms, who described feeling like ‘medical orphans’ [76]. Feeling unsupported in the post-diagnostic period highlights the need for interventions during this time and post-diagnostic support groups have been found to be beneficial for patients across physical and mental health [77]. The post-diagnostic period could be an opportune time to offer early intervention and support aimed at preparing patients for therapy.

For participants, a significant part of feeling in ‘limbo’ was the uncertainty of whether their diagnosis ‘fitted’. This was most often due to either limited confidence in the PNES diagnosis or through not identifying with a psychological explanation. For some, the psychological explanation was a particular challenge due to existing beliefs in a physical cause of the condition and for others, the explanation was experienced as a challenge to the person’s self identity, which has also been identified in previous studies focusing on patients’ experiences of the diagnosis [49, 50]. These difficulties with the diagnosis seemed to result in patients feeling in ‘no man’s land’. One potential explanation for this is that participants’ conflicting beliefs about their condition may create a state of discomfort or ‘cognitive dissonance’ [78]. Agreement with the diagnosis for some patients may be perceived as too distressing and therefore a state of ‘limbo’ is maintained which is potentially less threatening.

Understanding patients' difficulties concerning their diagnosis is important in light of this study's finding that the ways in which participants perceive their condition impacts on how they view psychological treatment. This finding is consistent with previous research [49, 53]. In particular, this study's findings suggest that enhancing patients' psychological understanding of their condition is likely to increase their optimism about therapy and this has been known to have positive implications for treatment engagement and success [55].

Theme 3: Uncertainty and apprehension about therapy

Patients described uncertainties about whether therapy would meet their needs. Underpinning this was a limited understanding of whether and how psychological therapy may be beneficial for PNES and a lack of understanding of the role of the psychologist. It is therefore understandable that research shows a significant number of patients with neurological functional symptoms do not attend their initial therapeutic appointment [57] and this group is acknowledged as difficult to engage [79]. Research into other conditions has found that providing information about therapy prior to an initial meeting can improve expectations, which may lead to better therapeutic outcomes [54]. This study's findings suggest that participants were unaware that they were being offered psychology because it is considered the treatment of choice for PNES [41, 42], rather than it being the 'only option' and this message could be communicated better.

Taking control was an important treatment need for participants in this study and contributed to their uncertainty about therapy. For some, medication was considered as a potential way of taking control and this was linked to ongoing beliefs in a physical cause. This supports previous suggestions that continuation of anti-epileptic medication can increase participants' uncertainties about diagnosis [34] and that withdrawal of medications may be an important part of reinforcing the diagnosis [74]; although this is likely to be resisted if the participant retains a physical illness attribution. For other participants in this study, there existed hope that psychology would aid in 'taking control', although most were uncertain if this was possible.

Apprehension and ambivalence also existed around the implications of taking control in terms of personal responsibility for the seizures. Taking control is identified as an important treatment goal for two popular treatment approaches in the literature on PNES [37, 38], although participants were largely unaware of these. Other psychotherapeutic models also deal with control [80, 81], although these at present do not have an established evidence base relevant to PNES.

A further key aspect of uncertainty about therapy was ambivalence and this can be a significant barrier to treatment. Ambivalence is typically considered early in therapy, often by emphasising that PNES can be psychological in origin but nevertheless involuntary [37]. The consequence of ambivalence not being addressed may be disengagement from the therapeutic process, both in terms of overt discontinuation of therapy and covert resistance such as not completing homework, arriving late and missing sessions [82]. Commencing treatment before people are ready to change can be counter-productive [83] and techniques designed to improve motivation could be conducted first. In the field of eating disorders, an area where patients are also thought hard to engage, motivational enhancement therapy has been found to be a promising development [84, 85]. Such techniques have not been studied in relation to PNES and further research in this area may be warranted.

Another treatment need, typically connected to feelings of apprehension about therapy, was a tendency for participants to 'bottle up' emotions. This was linked to a need for an 'emotional release' and this has previously been established as an important factor in PNES [86]. Participants also discussed keeping their emotions to themselves or hiding their emotions which, for some, seemed to be due to interpersonal difficulties of not being able to open up to significant others, due to feeling invalidated or dismissed. In these cases, psychodynamic interpersonal therapy (PIT) focused on addressing unhelpful ways of managing emotions and relating to others, may be a particularly useful approach [87]. This process can be challenging and can raise fears about being overwhelmed [88], which may be reflected in the ambivalence about 'delving' identified in this study. PIT addresses these concerns by

using the therapeutic relationship to create a place of safety and explicitly discussing fears at the start of therapy [89].

Theme 4: Need for validation

In this study, participants were relatively confident that the therapeutic relationship would provide validation and understanding that they hadn't found in other relationships. It is important to understand patients' values relating to the therapeutic relationship as it is an important predictor of therapeutic outcome [90]. The need for validation for many patients seemed to be linked to experiences of feeling disbelieved, discredited or not taken seriously by others. This has been replicated in other studies looking at the narrative of people with neurological medically unexplained symptoms (MUS) with 'legitimacy' being an important theme for these patients [73]; this was also replicated in patients with non-neurological MUS [91] and in chronic pain sufferers [92]. Issues of legitimacy may therefore be a characteristic of the experience of living with a medically unexplained condition.

All participants in this study reported an intention to attend their psychology appointment, despite feelings of uncertainty and ambivalence relating to the potential costs of therapy. At the time of the interview it seemed that for most, the potential positives of seeing the psychologist were outweighed by the perceived drawbacks. The theory of planned behaviour may be a useful model for understanding this intention to attend therapy. This model states intention is a function of a person's attitudes towards the behaviour, their subjective norms and their perceived ability to perform the given behaviour [93]. Factors relating to these areas were discussed by participants in this study but the opportunities to empirically test the influence of these factors on attendance would be useful for furthering knowledge on engaging this patient group.

Patients with PNES are known to be heterogeneous and this was reflected in the characteristics of the participants in this study. Although this sample was broadly representative in the demographic characteristics of the participants [11], a

psychopathological 'caseness' rate of 83% on the BSI is relatively high compared to previous studies [94] and may explain the high number of participants with either past or ongoing therapeutic involvement. A high number of participants were also identified as potentially being traumatised and some highly so, consistent with previous research on trauma prevalence in PNES patients [17]. This may have some bearing on the treatment needs that were discussed by patients, particularly those who identified suppression of feelings relating to past events and 'reliving' of experiences.

Limitations

The study has several limitations. Recruiting solely from a psychology waiting list meant that participants who did not wish to be referred to psychology and those not engaged with services were not represented in the study. The participants were self selecting, which may account for the high rate of psychopathology. Participants' perception that they were unsupported post diagnosis may reflect a biased sample who were particularly willing to volunteer for research where an opportunity to 'be heard' was on offer. Despite reassurances that the research was being conducted separately to the neuropsychology service, participants may have had concerns about 'opening up' and the role of the interviewer as a Trainee Clinical Psychologist may have influenced this and also introduced some social desirability.

Although the sample represented a heterogeneous group there was an absence of cultural diversity which limits the study. The study also only reflects the perspectives of patients who were diagnosed at one centre and therefore some experiences may be unique to this service, particularly as practice relating to PNES is so variable. This research found most participants had either identified an emotional link to their seizures or described being open to the explanation of one and this could be due to the high prevalence of past therapeutic involvement. This may also not represent the full range of patients diagnosed with PNES as those who may have completely rejected the possibility of a psychological explanation may not have taken part in this study.

Conclusion

Participants in this study had clear goals for their recovery and the ways in which these goals could be realised. However, following diagnosis, participants felt they were left in a state of uncertainty from which they did not know the way forward. This uncertainty linked to how they perceived psychological treatment and participants were unsure if therapy would meet their needs and some were ambivalent about engaging with therapy. Services could do more to support patients in the period following diagnosis and interventions to aid in the development of patient's understanding of their condition and their forthcoming treatment would be beneficial. The findings also have implications for how therapists may potentially engage these patients with a psychological approach.

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Critical Reflection

Introduction

The purpose of this critical reflection is to provide an overview and evaluation of the research presented in the literature review (paper 1) and empirical paper (paper 2). The lead researcher also offers her personal reflections of the research process throughout. The literature review will be addressed first, with consideration of the main findings, a critical evaluation of the methods, a discussion of potential limitations and reflections on the contribution to further research and clinical practice. In the second half of this paper, the author presents a personal reflection of carrying out a qualitative research study from the perspective of a novice qualitative researcher. The wider implications of the study's findings are discussed in relation to clinical implications and future research. An integrated summary of the two papers is then presented.

Critical Appraisal and Reflection on Literature Review

Reflections on Paper 1

The literature review aimed to bring together the current body of research that has investigated stakeholders' perspectives on PNES. There are no published reviews that have brought together perspectives research in this area. Twenty-five studies were included in the review, 15 representing various health professionals, ten representing patients with PNES and one representing general neurology patients. No further stakeholders were identified from the literature search. A narrative synthesis was conducted resulting in the identification of three main themes: perspectives on the nature of PNES as a condition; perspectives on diagnosis; and perspectives on management and treatment issues.

Differences were identified between the perspectives of professionals and patients in relation to perceived control of the condition and the use of terminology, which had the potential to cause patients offence or to feel 'disenfranchised' from services. This was thought to be clinically significant due to the potential impact this may have on

the development of an alliance between patients and professionals, which can influence outcomes and possible disengagement from therapy (Castonguay, Constantino, & Holtforth, 2006).

There were differences in professionals' views across the themes and professionals who were less experienced with PNES reported lack of certainty or confidence managing the condition. Similarly, patients reported feeling uncertain about PNES and were unsure of the 'best way forward'. The main strength of the review is that it is the first of its nature within PNES and brings together a disparate literature in a way that may be valuable for researchers and clinicians within this area.

Methodological Reflections

Focus of literature review

The main research paper explored perspectives of patients with PNES. The literature review was designed to complement this by providing a review of current research on views and perspectives of this condition. Patients often experience difficult and long 'journeys' to diagnosis during which failed or inappropriate treatment experiences are commonplace (Devinsky, Gazzola, & LaFrance, 2011). Understanding some of these challenges from the perspectives of patients was perceived as a potentially valuable addition to PNES research. Furthermore, professionals experience difficulties in providing an accurate diagnosis and effective treatment for PNES (Francis & Baker, 1999). Consequently, the focus of the review was not limited to patient perspectives but extended to a number of potential 'stakeholders' who may have important reflections relating to PNES. The researcher also thought that the existence of divergent opinions amongst stakeholders may have important clinical implications. The focus of the review was not restricted to perceptions of the condition but included the wider aspects of diagnosis, management and treatment of the condition, to allow for perspectives pertaining to a range of experiences.

Initially, the researcher investigated the possibility of restricting the review to purely qualitative accounts of perspectives. This resulted in the identification of only six papers that were varied in focus. It was felt that a meaningful synthesis could not be made of a small and broad body of research. Consequently, studies that investigated

perspectives, using quantitative methods, such as questionnaires, surveys and structured interviews, were included in the review. Although the studies had a broad focus there was a good quantity of papers to provide enough depth for an effective synthesis.

Literature search

There are numerous terms used academically and clinically to refer to PNES (Scull, 1997) and therefore a flexible search strategy was needed. Not all online journal databases are able to successfully run a complex adjacency search and therefore this limited the number of databases that could be included. The researcher decided that a flexible search approach was more of a priority for locating sources than increasing the number of databases. The databases used in this review were informed by those used by previous reviews relating to PNES (Bodde et al., 2009; Sharpe & Faye, 2006). The researcher's aim was to gain an exhaustive sample of the literature and therefore systematic searching of databases was followed by all abstracts of the returned papers being read. This was deemed important as reports of perspectives can often be found 'embedded' within broader research studies. Both forwards citation searching (studies citing the paper) and backwards citation searching (studies cited by the paper) was undertaken to ensure as many studies were located as possible. This has been identified as an important step for identifying additional papers in literature searches (Kuper, Nicholson, & Hemingway, 2006) and resulted in the identification of three further papers. Only published studies were included in the research which could potentially introduce a 'publication bias' into the review; however the benefits of this are that the included studies have undergone peer review and therefore a form of 'regulation' has been applied to these studies (Watson, 2012).

Quality Appraisal

Quality appraisals are seen as an integral part of systematic reviews of high quality treatment trials (Higgins et al., 2011), although the application of quality appraisal to qualitative studies has been debated (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). The potential value of appraising quantitative studies that capture perspectives is also unclear due to lack of well defined quality standards for such studies (Harden et al., 2004). To increase the quality of the appraisal approach the researcher chose two

published tools, the Critical Appraisal for Skills Programme tool (CASP, 2006) for qualitative studies and the Quality Assessment Criteria for Evaluating Primary Research Papers (Qualsyst; Kmet, Lee, & Cook, 2004) for the quantitative studies. The CASP is used for appraising qualitative studies and is one of the tools recommended by Cochrane for assessing study quality (Hannes, 2011). This tool was deemed suitable for this review as it can be used with a number of qualitative methodologies; however, one limitation of the tool is that it is generic and therefore lacks sensitivity. The QualSyst was developed from previously published tools (Cho & Bero, 1994; Timmer, Sutherland, & Hilsden, 2003) and was the only published tool the researcher could locate that provided enough flexibility to assess a broad range of quantitative studies; it does not seem to be a widely used tool, however.

The results of the quality assessments were second rated by a Trainee Clinical Psychologist also experienced in carrying out qualitative research. Any differences in ratings were discussed and a consensus was reached. Very little difference in opinion was found with regards the qualitative studies and it was reflected this may be as a result of the similar perspectives and experiences of the researchers. More disagreement was found on the quantitative measures; however, the prescriptive nature of the guidance for this tool aided in the development of a consensus.

The review did not exclude studies based on the quality assessment and this could be a potential limitation as including studies of poor quality has the potential to distort the subsequent synthesis (Dixon-Woods, Agarwal, Young, Jones & Sutton, 2004). However, in line with similar reviews (Barley, Murray, Walters, & Tylee, 2011) and following the guidance for narrative synthesis (Popay et al., 2006), no studies were excluded on the basis of quality. Therefore the strengths and weaknesses of the studies were considered during the analysis and communicated throughout the results. One advantage of including all studies is that conclusions can be made about potential limitations of the existing evidence base which can inform future research. This is particularly relevant considering this is the first literature review to bring together the research on perspectives of PNES.

Choice of Synthesis

Initially the researcher explored whether a meta-synthesis (Walsh & Downe, 2005) would be the most suitable approach for the literature review. Although debate exists about appropriate research questions and numbers of studies for a meta-synthesis (Downe, 2008), it was thought that completing a synthesis on a small number of qualitative papers with broad foci would result in a less meaningful review and a mixed methods review was therefore chosen. Inclusion of qualitative and quantitative research in a review has been considered to increase the utility and impact of the review (Harden, 2010), however there appears little agreement on the most effective method for integrating these different types of research. Narrative synthesis is a flexible review method that has been widely used but poorly demarcated prior to the recent publication of guidance (Popay et al., 2006). The purpose of the synthesis is simply to 'tell the story' of the data. The guidelines state the use of narrative synthesis can be appropriate when there are insufficient studies of a similar nature to allow for the use of other synthesis methods such as meta-analysis or meta-synthesis. However, the guidance for conducting a narrative synthesis asserts that it is not a 'second choice' for conducting a systematic review; indeed, one study has demonstrated that results from a narrative synthesis were broadly similar to the results from an independently conducted meta-analysis (Rodgers et al., 2009).

Narrative Synthesis Methodology

The main stages of this approach, as relevant to this review, were: developing a preliminary synthesis; exploring relationships within and between studies; and assessing the robustness of the synthesis. The initial step of the process is the development of a preliminary synthesis through tabulation of the main characteristics of the studies included in the review. This step identified the main patterns and areas of perspectives that the studies covered and the researcher began to develop initial ideas in relation to analysing the data. The results of the studies were then 'transformed' from quantitative to qualitative form to ensure that a 'common rubric' was created that allowed for comparing and contrasting of the results. Once data had been transformed it was analysed using principles of thematic analysis, an approach that is particularly suitable when there is a diverse range of evidence (Dixon-Woods, Agarwal, Young, Jones & Sutton, 2004). As the researcher was also conducting a

thematic analysis for her research study she drew on her existing knowledge of this approach and the available guidelines for conducting a thematic analysis for literature review (Thomas & Harden, 2008). The analysis involves line by line coding of results, development of initial themes and then identification of higher order themes through exploring relationships in the data. The analysis was derived using a data driven approach, however in developing the higher order themes the researcher was aware the aim of the review was to synthesise stakeholders' perspectives and therefore this also guided how the themes were developed. One potential criticism of this approach is that it can lack transparency (Pope, Mays & Popay, 2007) however by following published guidelines, as in the case of this review, this can be minimised.

Choice of journal

The audience of the paper is most likely to be professionals who work with PNES and those conducting research in this area. As PNES is a condition that 'falls' between medical and mental health services (Bodde et al., 2009), most PNES research is published in journals specifically relating to seizure disorders. For this reason, the epilepsy and seizure disorder journal, *Seizure – European Journal of Epilepsy*, was identified as the most appropriate target for this review.

Implications for future practice and research

The review highlights some differences between patients and professionals practices that could potentially impact on patients' experiences of health care services.

Terminology was an area of divergent opinion amongst stakeholders and had the potential to cause offence to patients. Further research into the specific views of patients with PNES of diagnostic terminology would also be useful as this review only identified one study of general neurology patients for whom this issue may be less relevant. Further research may also aid in the development of a consensus amongst stakeholders regarding an appropriate term for PNES, particularly as this seems to be the focus of some professional debate (Benbadis, 2010; Ramos, Ramos, & Ramos, 2010)

Professionals' uncertainties about different aspects of the condition highlight the need for an increased knowledge base regarding PNES. Due to the lack of evidence concerning effective treatments (Reuber & House, 2002) there is no consensus on a

‘treatment pathway’ or ‘best practice’ for PNES. Therefore further research is needed to increase the evidence base in this area. Professionals also discussed lack of confidence managing the condition and this may be addressed through more ‘experienced’ professionals working in consultation roles to extend the practice and knowledge of less experienced colleagues.

A general lack of qualitative research exists in relation to PNES and the ‘voice’ of patients and other stakeholders is under-represented in research. The earliest qualitative study in this review was completed in 2004, indicating this may be a developing area of research; however there is a pressing need for further qualitative studies on PNES. More in-depth research could also aid in understanding the development and influences of the views and perceptions represented in the quantitative studies.

A valuable addition to the research evidence would be gaining the perspectives of those who have lived with the condition for a number of years and particularly those who have experienced recovery. Understanding the process of recovery from a patient’s perspective can be useful in developing services that are targeted towards gaining meaningful outcomes for patients rather than recovery as defined clinically or by services (Slade, 2010). User led research can have an important role in understanding patients’ perspectives (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007) and may help to recruit hard to reach groups such as those not engaged with services.

More research is also needed on the perspectives of stakeholders that are not reflected in this review, such as the general public and family members of PNES patients. The wider view of PNES as captured by the general public would also be useful, particularly considering that patients with seizure disorders can often feel stigmatised (Morrell, 2002). Family members’ perspectives may also be particularly informative as family dysfunction has been identified as a predisposing, precipitating and perpetuating factor (Reuber, Howlett, Khan, & Grunewald, 2007). In other areas of psychological difficulty where families have been identified as significant, such as psychosis, research has helped to highlight family perspectives of the condition,

challenges they experience in their role and family perspectives of recovery (Bergner et al., 2008; Noiseux et al., 2010).

Critical Appraisal and Reflection on Empirical Paper

Reflective Summary

This study aimed to investigate in-depth the perspectives of PNES patients with regards their treatment needs. The study took a broad approach to understanding the context within which patients perceive their treatment and considered the processes underlying why patients may hold certain perspectives. Twelve semi-structured interviews were conducted and analysis of the interviews was carried out inductively following principles of thematic analysis. Four key themes were identified: return to normality; post-diagnostic limbo; uncertainty and apprehension about therapy; and need for validation. The findings indicate that patients have clear ideas about how they view recovery and subsequently are able to identify what needs should be addressed during treatment to achieve this recovery. It was also apparent that patients were less certain about whether therapy would meet their needs. Influencing this was a lack of certainty about their condition and the absence of post-diagnostic support and information about future progression. Also influential was the lack of knowledge of psychology and how it may benefit those with PNES. Some participants also described feeling apprehensive about therapy and this seemed to be linked by some to concerns about 'delving'. The study's value is that it not only highlights the reasons why patients with PNES may find treatment challenging following their diagnosis but also suggests potential ways to remediate this.

Methodological Reflections

Research Question

The research study aimed to identify patients' views of their treatment needs and forthcoming treatment. It was hoped that this study would be beneficial in helping to inform the development of services that are better able to meet the needs of patients with PNES. This was considered to be an important clinical issue due to the general lack of evidence available to professionals concerning the acceptability and

effectiveness of treatments for PNES (Reuber & House, 2002). The research question was developed through discussions between the lead researcher and her supervisor (RB). A wider research team with a special interest in PNES was also consulted. These researchers had an in-depth knowledge of the current research and knew where important 'gaps' in the evidence were.

It was thought a particularly important research question given the emphasis placed by the UK government on seeking service user views to inform the development of health care services and services that are needs led and patient centred (Mockford, Staniszewska, Griffiths & Herron-Marx, 2012). There is a growing acknowledgement that patients are experts in their experiences and may have valuable reflections of these experiences in relation to services and managing the condition (Glasby et al. 2003). It has also been acknowledged that service user involvement can be personally beneficial for service users, resulting in feelings of involvement, helping others and an increased sense of self esteem (Minogue, Boness, Brown, & Girdlestone, 2005).

The researcher held an interest in the area due to an awareness of PNES developed in a previous role, although she had no direct clinical experience with the patient group. The researcher was aware that it was a complex and developing area of research and there was discussion amongst the research team that at times patients with PNES could be a relatively difficult group to recruit. The researcher was also keen to gain experience of qualitative methods as this was thought to be a 'gap' in her research skills.

Choice of Qualitative Methods versus Quantitative Methods

Qualitative methods were chosen as they are suitable for an area where little research has been completed and the focus of the study is exploratory (Mays, Pope, & Popay, 2005). A quantitative survey approach could have been used to gain views of patients with PNES and the advantages of this would have been the opportunity to recruit a larger sample and the potential to generalise the research findings. However the disadvantages of this approach are that it allows little further exploration of views and does not allow for a detailed understanding of the reasons for participants' perspectives; this 'why' question is something that can potentially be addressed by

qualitative methods. Quanti-qualitative approaches may also have been suitable methodologies to investigate the research question, such as Q methodology (Stephenson, 1953) or the repertory grid technique; devised from Personal Construct Theory (Kelly, 1955). These techniques were potentially suitable as they involve, respectively, the systematic investigation of a person's subjective views or construal of the world. However, as many strands of inquiry were thought potentially relevant to the research question in this study, employing interviews for data collection provided the most flexibility to allow for an in-depth, iterative exploration of perspectives pertaining to the research question.

Although qualitative methods were considered the most appropriate approach for this research question, there are a number of criticisms often made of qualitative methods such as concerns about reliability, the generalisability of findings and researcher bias (Mays & Pope, 1995). The ability to reproduce results is often criticised in qualitative research due to the lack of indices of reliability in contrast to quantitative research. Doubts about the ability to generalise the results often relate to the small participant numbers typical of qualitative studies. These criticisms often arise due to qualitative research being assessed under the same principles that are applied to quantitative research, whereas often the purposes of these two different methods of investigation are very different (Golafshani, 2003). It has been proposed that qualitative research should be assessed in terms of dependability (findings are consistent and could be repeated), credibility (confidence in the truth of the findings) and transferability (findings are applicable to others contexts) as opposed to traditional concepts of research quality (Lincoln and Guba, 1985). However, no consensus has been reached on this debate.

In this study, the researcher used the concepts of reliability and validity to describe the quality of her research. The methods employed by the researcher to ensure quality, such as the use of a research diary and credibility checks, were informed by published guidelines for conducting rigorous qualitative research (Elliott, Fischer, & Rennie, 1999; Yardley, 2000). However, there were limitations to the quality of the research, such as the lack of inter-rater reliability and respondent validation, which could not be carried out due to the time constraints of the research.

Developing the interview guide

The main areas of the research interview guide were discussed in an initial meeting with the lead researcher and her two supervisors, one an experienced clinician and researcher with PNES (RB) and the other an experienced qualitative researcher (JF). The main areas of the guide were agreed in this meeting. These initial ideas were developed by the researcher, drawing on her awareness of the literature relating to treatment needs for PNES. Consensus on the interview guide was then gained from a number of experienced researchers and clinicians with PNES, identified through the research network of the main supervisor (RB).

The researcher drew on published principles for developing an interview guide suitable for use during semi-structured interviews (Smith & Osborn, 2008). The sequencing of questions was considered, with initial questions relating to the participant's understanding of the condition to provide some context, working towards the later questions relating to expectations of psychology. Questions were neutrally worded and designed not to be leading, used minimal jargon and were designed to be open in nature to encourage in-depth discussion.

Sampling and Recruitment

In line with qualitative methodology, purposive sampling was used for this research. This is a process for selecting a sample on the basis of a particular characteristic, in this case patients who were awaiting treatment for their PNES, that allows for detailed exploration of the research question (Ritchie & Lewis, 2003). Newly diagnosed patients were identified in an attempt to keep the sample homogenous, which also allows for in-depth exploration of an issue (Patton, 2002). The eventual sample size was either comparable to or greater than other qualitative studies with this patient group (Baxter et al., 2012; Green, Payne, & Barnitt, 2004; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009) and other published thematic analyses (Griffiths, Norris, Stallard, & Matthews, 2012; Lack, Noddings, & Hewlett, 2011).

Initially, the research was designed as a multi-centre study and recruitment was therefore intended to encompass a Neuropsychology and a Neurology Department. Due to changes in the role of the field supervisor recruitment was no longer possible at

this latter site, despite ethical approval being gained for this. Consequently, this limited the recruitment to the single service, potentially increasing the likelihood that results were reflective of local practices. It also potentially limited the opportunity to recruit those patients who were newly diagnosed with PNES but did not consent to be referred to a psychology service.

Recruitment was conducted in two waves to ensure the burden on the recruiting service was limited and the research was therefore supportable. The limitations of this were that a gap occurred between the two recruitment waves. As the research was inductive, the researcher experienced this gap in data collection as disruptive to the 'momentum' of the research. The researcher found it more difficult to hold in mind the previous interviews and analysis from the first wave but remedied this by spending time revisiting and familiarising herself with her reflective diary, transcripts and analysis to date.

Ethical Issues

As the sample had a high representation of psychopathology and symptoms of trauma it was understandable that risk issues were an aspect of the research process. Where risk issues arose the researcher gained appropriate supervision from her field or research supervisor. As the interviewer worked clinically as a Trainee Clinical Psychologist she was familiar with risk assessment procedures and, where necessary, further communication was made with the most relevant service regarding risk issues. This was discussed openly with participants and in all cases they were aware of the need to share the information and were in agreement with this.

Not all participants presented as being at risk although many were distressed. Therefore patients were given an information sheet listing contacts for support groups, websites for information relating to PNES and also more 'non-specific' support services, such as the Samaritans. Due to the interviewer being a Trainee Clinical Psychologist she was experienced in managing highly emotive situations and this benefitted her ability to manage these situations sensitively.

Interviews

The researcher's initial experience of carrying out the research interviews was that she had a tendency to remain 'close' to the interview guide. This was due to inexperience and uncertainty related to embarking on a new research method and concerns that she might miss something if she strayed from the guide. However, as the interviews progressed and the researcher's confidence in the process increased, there was a greater fluidity in the use of the interview guide which seemed to increase the quality of the data collected. The process of the research interview was experienced by the researcher as very different to clinical interviewing and this took time for her to adjust to. Further guidance on how to question and provide additional prompts in a way that is suitable to interviewing for qualitative methodologies was found to be valuable (Ritchie & Lewis, 2003). Use of the reflective log helped to develop interviewing skills further and also the experience of transcribing interviews helped the researcher to reflect upon her questioning that further helped develop her interviewing style.

Choice of Thematic Analysis

There are a number of qualitative approaches that could have been used to explore patients' perspectives of treatment needs. As the researcher was a novice to qualitative methods, the choice of methodology was made in collaboration with an experienced qualitative researcher, as this is a crucial part of designing a qualitative study. There was agreement that in understanding the perceived treatment needs of patients with PNES, an exploration of context and processes underpinning these perspectives was needed; an interpretive and inductive approach using either Grounded Theory (Charmaz, 2006) or thematic analysis (Braun & Clarke, 2006) was therefore considered. Consequently, phenomenological approaches that focus on the 'lived experience' of participants were excluded as they did not fulfil the research aims.

Thematic analysis was chosen as the most suitable approach as it was felt that the potential to carry out theoretical sampling, one of the central tenets of Grounded Theory, was limited due to projected constraints in recruitment. Although an inductive thematic analysis is similar to grounded theory, they are distinct in that thematic analysis does not result in a fully worked up theory.

Thematic analysis can be considered quite a poorly demarcated approach, although it is often the approach used in qualitative studies and underpins other 'branded' methodologies. There is little guidance about how to conduct a good thematic analysis with only a few specific sources (Boyatzis, 1998; Braun & Clarke, 2006). This is a potential challenge to a researcher who has little experience in the field and therefore supervision was invaluable in guiding the process.

Use of the reflective diary

Use of the reflective diary can be thought of as the "personal tale of what went on in the backstage of doing research" (Ellis & Bochner, 2000, p. 741). It is a useful way of locating the researcher within the research or a way of 'owning one's perspective' that is important in maintaining reflexivity (Elliott, Fischer & Rennie, 1999). This is important in terms of bias as the researcher is seen as an important part of the construction of the research. The researcher found the reflective diary a useful place to explore and develop ideas relating to the information shared in the interviews. The researcher found it useful to complete their research diary as soon as they left the research interview to capture thoughts when they were most salient. Additional reflections were made through the transcription and coding phase of the research to capture thoughts as they developed during these processes.

Engaging with the literature

There are different ideas about when a researcher should engage with the literature around their research area. An inductive approach to research can mean that the researcher does not engage with the literature during data collection. As the researcher was a novice to this area, not engaging with the literature, aside from some provisional reading to help formulate the aims for the study and develop the interview guide, this did not present as a difficulty. However, before data collection was finished the researcher completed her literature review of stakeholders' perspectives of PNES due to the time pressures of her doctoral training course. As little qualitative research exists in relation to PNES in this area, the influence of exposure to the literature was thought to be minimal, however it highlighted to the researcher the balance that needs to be made between maintaining high methodological rigour and carrying out 'real world' research to deadlines.

Analysis

The process of coding at first seemed elusive and at times challenging to the researcher. Using a process of open coding meant the researcher was sometimes uncertain how interpretive to be and due to these apprehensions initially stayed overly 'close' to the data and tended to develop codes that were descriptive in nature. Supervision from an experienced qualitative researcher helped the shift in coding to a more 'latent' level (Boyatzis, 1998), which aided in the exploration of underlying assumptions and processes in the data.

The researcher was also reassured that the process of coding was on-going and therefore codes could be refined over time. The process of memo writing helped the researcher to develop her coding through explicit questioning of the data and by drawing out differences and similarities that informed the further development of codes. Guidance and examples provided by qualitative research handbooks were helpful in the process of coding (Flick, 2006), although the researcher discovered that the best way to develop her competence was through continued engagement in the process.

At times the simultaneous data collection and analysis was challenging for the researcher due to time pressures and space for reflection was sometimes difficult. However, the researcher found the iterative process invaluable for developing ideas and asking questions of the data that then informed 'new avenues' of investigation (Pope, Ziebland, & Mays, 2000). Analysis of the data took longer than the researcher anticipated and there were times when the amount of data felt overwhelming and unclear. On reflection, the thematic analysis was made further unclear by the uncertain and ambiguous accounts of the participants contained within the data. Thematic structures were revised on several occasions and the researcher felt new understandings of the data continued to be made.

Writing up

As defined in Braun and Clarke (2006) the process of writing up can be viewed as part of the analysis process. The researcher found that the process resulted in further questioning of the data and this prompted her to revisit the analysis to ensure that a

coherent account of the data had been made. However, the researcher was also aware that qualitative analysis can continue *ad infinitum*. The researcher felt that the themes were so broad that it was difficult during write up to provide space for individual accounts, 'anecdotes' and narratives. The researcher felt this was a limitation of the study due to the richness of the data that she had collected, but that the research question was better answered with the broad focus of the themes.

Reflections on Carrying out Qualitative Research

Carrying out qualitative research is challenging for the novice researcher. Articles and books provide direction about qualitative methods, but it seemed to the researcher that the true nature of the research process only became clear once engaged with it. This at times felt very uncertain for the researcher, although supervision helped to normalise that this was a typical experience when first embarking on qualitative research. Developing skills in qualitative research was seen as beneficial for her career as a Clinical Psychologist where research is an integral part of the role.

Implications for practice and further research

The aim of this thesis was to carry out a clinically relevant piece of research. Implications from this piece of research are most likely to be relevant to those who work closely with people with PNES such as neurologists, psychotherapists, psychiatrists, clinical psychologists, family therapists and cognitive behavioural therapists. Therefore an epilepsy journal, *Epilepsy & Behavior*, was chosen for publication.

Participants in this study were certain about their treatment needs, these were: finding answers; gaining an emotional release; and taking control. However there was an uncertainty whether therapy would meet these needs. There was also a general need to feel validated and the participants were more optimistic they may gain this from the psychologist. Patients' discussion of their treatment needs fit with the aims of the two main psychological treatments for PNES, Psychodynamic Interpersonal Therapy (PIT) and Cognitive Behavioural Therapy (CBT), although most patients had no awareness of these specific therapies.

PIT is one of the approaches currently being developed for patients with PNES and a good account of the process of this therapy has been provided in the academic literature, although randomised trials are lacking (Howlett & Reuber, 2009). One of the first foci of this therapy is to discuss apprehensions and ambivalence about therapy, which is clearly relevant to patients' accounts in this research. This allows the patient to be open about how they feel about therapy, for the therapist to offer empathy to the patients and for interpersonal and emotional themes relating to their ambivalence to be identified and explored. 'Finding answers' was an important treatment need for patients and this can be considered to be met by PIT through the development of a longitudinal formulation early on in the therapy process, drawing on a broad spectrum of information. 'Taking control' is also a treatment need that can be met by this therapy as symptom control techniques such as sensory grounding and stress reduction techniques are developed. One central aim of PIT is also to increase patients' independence and this resonates with the accounts of participants in this study whose 'return to normality' included an increase in their independence. Gaining an emotional release is central to PIT therapy and, once a safe therapeutic relationship is established, difficult experiences and emotions can then be addressed and more helpful ways of 'gaining a release' identified.

CBT is also another approach that may meet the treatment needs described by the patients and a good account of the therapy has been given by recent research, although outcomes evidence is limited and equivocal (Goldstein et al., 2010). Again the therapy focuses on providing answers early on in the therapy process through the development of a formulation with the patient. Validation is central to the earlier sessions with explicit communication that the patient's seizures are real and that they are not perceived by the therapist as 'put on' or feigned. 'Gaining control' of the seizures is also facilitated by this therapy through the use of distraction or 'refocusing' techniques and also through applying relaxation and controlled breathing exercises. It is less obvious from accounts of the literature how current CBT approaches for PNES foster 'emotional release', particularly in relation to past traumas, although this is something that can be addressed through CBT.

Other models of psychological therapy may offer potential benefits to patients with PNES, although they lack an established evidence base for this group at present. Issues of control (as discussed in this study) are central to Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) where strategies of emotional control are identified as increasing a person's psychological distress in the long term. Equally issues of control are key in Method of Levels therapy (MOL; Carey, 2006) where distress is conceptualised as arising from a disruption in control. These therapies address issues of control differently, with ACT aiming for patients to 'let go' of their control strategies through mindfulness-based techniques, whereas MOL therapy aims for patients to restore control through addressing internal conflicts. Another therapeutic approach, Cognitive Analytical Therapy (Ryle, 1995), may be an appropriate approach for some patients with PNES as it addresses 'gaining answers' through the development of a reformulation that places difficulties within the context of interpersonal relationships. This is something that was identified as important by the participants in this study.

Uncertainty and ambivalence in relation to therapy were identified, consistent with previous findings that engaging patients with functional symptoms in therapy can be challenging (Guthrie, 1996; Howlett, Grünewald, Khan, & Reuber, 2007). There are a number of potential interventions that could target this aside from PIT. It has already been established shown that providing information to patients about the therapy process can be helpful (Dew & Bickman, 2005) but this had apparently not been provided to the patients in the current study. Motivational interventions may also be useful for increasing patient's readiness for change (Miller & Rollnick, 2002). These could be implemented at the start of a therapeutic process but may be more beneficial in the period prior to commencing therapy. Motivational enhancement therapy draws on Prochaska and DiClemente's stages of change model (1983) and aims to facilitate the patient through the stages towards maintenance of change. It is a non-confrontational approach and this may be key for patients with PNES considering their ambivalence. Motivational enhancement therapy was originally developed within the field of alcohol and substance use (Miller, Zweben, DiClemente & Zychtarik, 1995) but research is developing in other conditions where patients are known to be ambivalent

and difficult to engage, such as eating disorders (Feld, Woodside, Kaplan, Olmsted, & Carter, 2001; Katzman et al., 2010).

The research highlights the need for patients to have a better understanding of their condition following their diagnosis, since having no post-diagnostic support seems to increase the challenges faced by patients. For patients to understand the rationale for therapy they first need to understand the condition from a psychological point of view. This is where services could better support patients and increase the likelihood that patients can engage in a treatment that may be potentially beneficial. Steps forward could include increasing patient's understanding of psychological treatment and acknowledging patient's potential apprehensions at the outset of therapy.

Integrated Summary of Research

Throughout the research process, it was clear that there are a number of 'unknowns' and confusion about PNES. As research on PNES is still in its infancy these papers make significant contributions to the growing field of perspectives research in this area. Across both papers there appears to be a significant collective uncertainty amongst patients and professionals with regards to PNES. Relationships between patients and professionals were identified as difficult at times in both the literature review and the empirical paper, often due to a number of clinical disappointments. Patients are faced with a number of challenges upon receiving a diagnosis of PNES and can find the experience a distressing time. The research across both papers suggests that post-diagnosis patients feel uncertainty about the 'way forward', particularly in relation to psychology. The task therefore for professionals and those with a stake in the care of PNES is to acknowledge the current gaps in knowledge and practice and move forward to developing services that are acceptable to patients and are effectively meeting patients identified needs.

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Appendices

Appendix 1:

Submission Guidelines for Seizure – European Journal of Epilepsy

SEIZURE - EUROPEAN JOURNAL OF EPILEPSY

AUTHOR INFORMATION PACK

GUIDE FOR AUTHORS

INTRODUCTION

Types of articles

Seizure - European Journal of Epilepsy publishes the following types of article:

1.1 Peer-reviewed articles

a. Full reviews.

Seizure welcomes comprehensive reviews on all subjects relating to epilepsy and other seizure disorders. Authors planning/proposing are invited to discuss their ideas with Editor-in-Chief prior to submission. Full reviews should be preceded by an abstract. Full reviews should not exceed 7,000 words, include no more than six figures or tables and 150 references.

b. Focused reviews.

Seizure is keen to publish focused reviews, especially on the latest developments in particular fields or on topics which are currently debated by clinicians and researchers. Authors are welcome to approach the Editor-in-Chief with their idea for a focused review prior to submission. Focused reviews should be preceded by an abstract. Focused reviews should be 1,500-2,500 words, and include no more than three figures or tables and 50 references.

c. Full-length original research articles.

The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of six figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Discussion, 4) Conclusion and 5) References.

d. Brief communications.

Comprise a number of different kinds of previously unpublished materials including short reports or small case series. Brief communications should be preceded by an abstract. The body of the text is limited to 1,400 words. There are no more than twelve references, and two figures or tables (combined).

e. Case reports.

Seizure will also publish particularly instructive case reports. Case reports will not be preceded by an abstract. The word count is limited to 1,400 words. Case reports should provide a maximum of twelve references, and two figures or tables (combined).

1.2 Editorially-reviewed material

Other contributions than original research or review articles will be published at the discretion of the Editor-in-Chief, with only editorial review. Such material includes: obituaries, workshop reports and conference summaries, letters/commentary to the Editors (500 word limit, exceptionally including figures or tables), special (brief) reports from ILAE Commissions or other working groups, book reviews and announcements.

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The Editor-in-Chief invites ideas for supplements or special editions of *Seizure* including meeting abstracts. Such materials may be published, but only after prior arrangement with the Editor-in-Chief. Supplements will incur a charge. The page rate for proposed supplements can be negotiated with the Editor-in-Chief. Special editions are issues of *Seizure* wholly or partially dedicated to one particular topic. They may be edited or co-edited by internationally recognised experts in their field. Such experts do not need to be members of the Editorial Board of *Seizure* and are welcome to approach the Editor-in-Chief with their ideas. Special editions of *Seizure* would be expected to contain the same kind of manuscripts which are published in normal editions.

BEFORE YOU BEGIN

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PREPARATION

Use of wordprocessing software

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To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your wordprocessor.

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when crossreferencing text: refer to the subsection by heading as opposed to simply 'the text'.

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. Only in case of short communications, the results and discussion sections may be combined. Results should usually be presented in graphic or tabular form, rather than discursively. There should be no duplication in text, tables and figures. Experimental conclusions should normally be based on adequate numbers of observations with statistical analysis of variance and the significance of differences. The number of individual values represented by a mean should be indicated.

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. Speculative discussion is not discouraged, but the speculation should be based on the data presented and identified as such. In most cases a discussion of the limitations is appropriate and should be included in this section of the manuscript.

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.

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Abbreviations

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Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

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Follow internationally accepted rules and conventions: use the international system of units (SI). If other quantities are mentioned, give their equivalent in SI. You are urged to consult IUPAC: Nomenclature of Organic Chemistry: <http://www.iupac.org/> for further information.

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- GEO: Gene Expression Omnibus (GEO ID: GSE27196; GEO ID: GPL5366; GEO ID: GSM9853)
- MI: EMBL-EBI OLS Molecular Interaction Ontology (MI ID: 0218)
- MINT: Molecular INTERactions database (MINT ID: 6166710)
- NCBI Taxonomy: NCBI Taxonomy Browser (NCBI Taxonomy ID: 48184)
- NCT: ClinicalTrials.gov (NCT ID: NCT00222573)
- OMIM: Online Mendelian Inheritance in Man (OMIM ID: 601240)
- PDB: Worldwide Protein Data Bank (PDB ID: 1TUP)
- TAIR: The Arabidopsis Information Resource database (TAIR ID: AT1G01020)
- UniProt: Universal Protein Resource Knowledgebase (UniProt ID: Q9H0H5)

Math formulae

Present simple formulae in the line of normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number

consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

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Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Table footnotes

Indicate each footnote in a table with a superscript lowercase letter.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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Examples:

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1. Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. *J Sci Commun* 2010;**163**:51–9.

Reference to a book:

2. Strunk Jr W, White EB. *The elements of style*. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

3. Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. *Introduction to the electronic age*, New York: E-Publishing Inc; 2009, p. 281–304.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (*J Am Med Assoc* 1997;**277**:927–34) (see also http://www.nlm.nih.gov/bsd/uniform_requirements.html).

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Journal names should be abbreviated according to

Index Medicus journal abbreviations: <http://www.nlm.nih.gov/tsd/serials/lji.html>;

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- Keywords
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Further considerations

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Appendix 2
Search Terms for Literature Review

((((Nonepileptic or non-epileptic or non epileptic or dissociative or psychogenic or functional or pseudoneurological or pseudoepileptic) adj1 (Seizure\$1 or convulsion\$1 or attack\$1 or fit\$1 or pseudoseizure\$1)) or (Pseudoseizures or psychogenic nonepileptic or psychogenic non epileptic or psychogenic non-epileptic)) and (Perspective\$1 or view\$1 or perception\$1 or attitude\$1 or experience\$1 or opinion\$1 or understand\$ or narrative\$1 or expectation\$1 or survey or qualitative)).ab,ti.

Appendix 3
Results of quality appraisal for qualitative studies

Appendix 3: Table showing results of quality assessment for qualitative papers.

Questions	Baxter et al 2012	Dickinson 2011	Green 2004	Thompson 2009	Karterud 2010	Quinn 2010
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Part	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Part	Yes
5. Were the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	No	No	No	Yes	No	Yes
7. Have ethical issues been taken into consideration?	Yes	Yes	Part	Part	Yes	Yes
8. Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Part	Yes	Yes
9. Is there a clear statement of findings?	Yes	Part	Yes	Yes	Yes	Yes
10. How valuable is the research?	Yes	Yes	Yes	Yes	Yes	Yes
Quality Assessment Percentage Score	90%	85%	85%	90%	80%	100%

Appendix 4
Results of quality appraisal for quantitative studies

Appendix 4: Table showing results of quality assessment for quantitative papers.

	Benbadis	Carton	Ettinger a	Ettinger b	Hall-Patch	Harden	LaFrance	Mayor	Morrison & Razvi	O'Sullivan	Oto	Sahaya	Schachter	Shneker & Elliott	Specht & Thorbecke	Stagno & Smith	Stone et al	Whitehead & Reuber	Worseley
1. Question or objective sufficiently described?	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)
2. Design evident and appropriate to answer study question?	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Part (1)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)
3. Method of study selection or source of information/ input variables is described and appropriate.	Part (1)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Part (1)	Part (1)
4. Subject characteristics or input variable/information sufficiently described?	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	No (0)	Yes (2)	Part (1)	No (0)	Yes (2)	Yes (2)	Yes (2)
5. If random allocation to treatment group was possible, is it described?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators to intervention was possible, is it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects to intervention was possible, is it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure method/s well defined and robust to measurement / misclassification bias? Means of assessment reported?	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)
9. Sample size appropriate?	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	N/A	N/A	N/A	N/A	Yes (2)	N/A	Yes (2)	Yes (2)	N/A	N/A	Yes (2)	Yes (2)	Yes (2)
10. Analysis described and appropriate?	Yes (2)	Part (1)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)
11. Some estimate of variance is reported for the main results/outcomes?	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Part (1)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)
12. Controlled for confounding?	No (0)	Part (1)	Part (1)	Part (1)	N/A	Part (1)	N/A	N/A	N/A	N/A	Part (1)	N/A	Part (1)	Yes (2)	N/A	N/A	N/A	Part (1)	Part (1)
13. Results reported in sufficient detail?	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)
14. Do the results support the conclusions?	Part (1)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Yes (2)	Part (1)	Part (1)	Part (1)	Part (1)	Part (1)	Part (1)	Part (1)	Part (1)	Part (1)	Yes (2)	Yes (2)	Part (1)	Yes (2)
Quality Assessment Total and Percentage Score	15/22 68%	17/22 77%	21/22 95%	21/22 95%	19/20 95%	20/22 91%	16/18 89%	17/18 94%	16/18 89%	16/18 89%	16/22 73%	15/18 83%	15/22 68%	20/22 91%	15/18 83%	15/18 83%	20/20 100%	19/22 86%	20/22 91%

Appendix 5

Epilepsy & Behaviour: Author Guidelines

Guide for Authors

Epilepsy & Behavior has been, and still is, the fastest-growing international journal since its launch nearly six years ago. *Epilepsy & Behavior* is uniquely devoted to the rapid dissemination of the most current information available on the behavioral aspects of seizures and epilepsy.

Epilepsy & Behavior presents original peer-reviewed articles based on laboratory and clinical research. Topics are drawn from a variety of fields, including clinical neurology, neurosurgery, neuropsychiatry, neuropsychology, neurophysiology, neuropharmacology, and neuroimaging.

Epilepsy & Behavior publishes papers on the study of:

- Localization of ictal and postictal behaviors
- Neuroendocrine aspects of epilepsy
- Psychiatric and psychosocial aspects of epilepsy
- Behavioral aspects of epilepsy surgery
- Cognitive and affective effects of seizure treatment
- Functional imaging
- Animal models

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Preparation of Manuscripts

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The **Title Page** (p. 1) should contain the article title, authors' names and complete affiliations, footnotes to the title, and the address for manuscript correspondence (including e-mail address and telephone and fax numbers). Please note that proprietary names for drugs should *not* be used in the article title.

The **Abstract** (p. 2) must be a single paragraph that summarizes the main findings of the paper in less than 150 words. After the abstract a list of up to 10 keywords that will be useful for indexing or searching should be included.

The **Introduction** should be as concise as possible, without subheadings.

Methods should be sufficiently detailed to enable the study to be reproduced.

Results and **Discussion** should be separate and may be organized into subheadings.

Acknowledgments should be brief and should precede the references.

References should be cited in the text by numbers in brackets, in order of appearance and follow the Vancouver Style ([↗](http://www.library.uwa.edu.au/guides/citingsources/vancouver.html) <http://www.library.uwa.edu.au/guides/citingsources/vancouver.html>). Only articles that have been published or are in press should be included in the references. Authors are responsible for the accuracy of references. Unpublished results or personal communications should be cited as such in the text. Please note the following examples:

[1] Hermann BP, Seidenberg M, Bell B, Woodard A, Rutecki P, Sheth R. Comorbid psychiatric symptoms in temporal lobe epilepsy: association with chronicity of epilepsy and impact on quality of life. *Epilepsy Behav* 2000;1:184-90.

[2] Paxinos G, Ashwell KWS, Tork I. Atlas of the developing rat nervous system. 2nd ed. San Diego: Academic Press; 1994.

[3] Shafer PO, Salmanson E. Psychosocial aspects of epilepsy. In: Schachter SC, Schomer DL, editors. The comprehensive evaluation and treatment of epilepsy: a practical guide. San Diego: Academic Press; 1997. p. 91-109.

Figures. Number figures consecutively with Arabic numerals. Please visit our Web site at [↗](http://authors.elsevier.com/artwork) <http://authors.elsevier.com/artwork> for detailed instructions on preparing electronic artwork.

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Color figures for exclusive use as **cover illustration** may be submitted by authors who are also submitting a manuscript for consideration. These figures should relate to the manuscript being submitted as well as the larger scope and focus of *Epilepsy & Behavior*.

Figure legends should be submitted on a separate page. Figure legends should be concise descriptions of the illustration. Detailed information pertaining to the figure should be included within text, with the appropriate reference to the figure number.

Tables should be numbered consecutively with Arabic numerals in order of appearance in the text. Give each table a short descriptive title typed directly above it, with essential footnotes below.

Ethics

Manuscripts submitted for publication must contain a statement to the effect that all human studies have been approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. It should also be stated clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under study should be omitted. Reports of animal experiments must state that the "Principles of laboratory animal care" (NIH publication No. 86-23, revised 1985) were followed, as well as specific national laws (e.g. the current version of the German Law on the Protection of Animals) where applicable. The Editors reserve the right to reject manuscripts that do not comply with the above-mentioned requirements. The author will be held responsible for false statements or for failure to fulfill the above-mentioned requirements.

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Appendix 6

Confirmation of NRES Ethical Approval



National Research Ethics Service

NRES Committee North West - Liverpool East

North West REC Centre
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7373

20 July 2011

Miss Gillian Fairclough
Trainee Clinical Psychologist
Manchester Mental Health and Social Care NHS Trust
Division of Clinical Psychology,
2nd Floor, Zochonis Building,
Brunswick Street
Manchester
M13 9PL

Dear Miss Fairclough

Study title: Understanding the perceived treatment needs and expectations of psychological therapy amongst people with Non-Epileptic Attack Disorder: A Qualitative Study
REC reference: 11/NW/0376

Thank you for your letter of 13 July 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to the North West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	1	27 April 2011
Covering Letter		27 May 2011
Evidence of insurance or indemnity		25 May 2011
Interview Schedules/Topic Guides	1	27 April 2011
Investigator CV	CI	25 May 2011
Investigator CV	Supervisor	17 May 2011
Letter from Sponsor		25 May 2011
Other: Support Groups, Helplines and Sources of Further Information	1	27 April 2011
Other: Managing a non-epileptic attack	1	27 April 2011
Other: Distress Protocol	1	27 April 2011
Other: Reminder Letter	1	01 July 2011
Participant Consent Form	1	27 April 2011
Participant Consent Form	1	27 April 2011
Participant Information Sheet	2	01 July 2011
Protocol	2	01 July 2011
Questionnaire: Brief Symptom Inventory		
Questionnaire: Trauma Symptom Checklist		
Questionnaire: Relationship Scale		
Questionnaire: Demographics	1	27 April 2011
REC application	70731/21766 3/1/860	27 May 2011
Referees or other scientific critique report		07 February 2011
Response to Request for Further Information		13 July 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

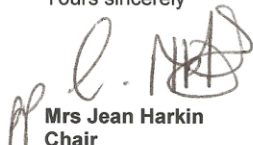
Further information is available at National Research Ethics Service website > After Review

11/NW/0376

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely


Mrs Jean Harkin
Chair

Email: charlene.mike@northwest.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Nalin Thakker
University of Manchester

Ms Tanya Loughran
Sheffield Teaching Hospitals NHS Foundation Trust

Appendix 7

Local NHS Research and Development Approval



Greater Manchester
Primary Care Research Governance Partnership



NHS SalfordR+D
Acute & Primary Care Research

NHS SalfordR+D Director:
R&D Lead:

Professor Bill Ollier
Rachel Georgiou

SalfordR+D web address: <http://www.nhssalfordrd.org.uk/>
ReGroup web address: <http://www.gmregroup.nhs.uk/index.html>

8th August 2011

Miss Gillian Fairclough
Trainee Clinical Psychologist
Manchester Mental Health and Social Care NHS Trust
Division of Clinical Psychology,
2nd Floor, Zochonis Building,
Brunswick Street, Manchester M13 9PL

Dear Ms Fairclough

Study Title: Understanding the perceived treatment needs and expectations of psychological therapy amongst people with Non Epileptic Attack Disorder: A Qualitative Study
REC Reference: 11/NW/0376
EuDraCT Reference: N/A
R&D Reference: 2011/161NEURO

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS SalfordR+D and has gained NHS R&D approval from the following NHS Trusts:

- Salford Royal NHS Foundation Trust

All clinical research must comply with the Health and Safety at Work Act, www.hse.gov.uk and the Data Protection Act. <http://www.hmsa.gov.uk/acts>

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The 'Research Passport Application Form'. This can be obtained from web addresses: <http://www.gmregroup.nhs.uk/researchers/passports.html> and <http://www.hope-academic.org.uk/academic/salfordrd/Research%20Passports.html>. This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.

Research & Development Department
Ground Floor, Summerfield House,
544 Eccles New Road, Salford M5 5AP

Appendix 8

Participation Information Sheet

Division of Clinical Psychology
2nd Floor, Zochonis Building
University of Manchester
Brunswick Street
Manchester M13 9PL
Tel: 0161 306 0400

TREATMENT NEEDS OF PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER PARTICIPANT INFORMATION SHEET

Please read this sheet carefully.

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the study about?

We would like to understand more about the views and perspectives of people with Non-Epileptic Attack Disorder (NEAD). The first aim of this study is to understand what people with NEAD think about their treatment and treatment needs. The second aim of this study is to understand what people with NEAD think about psychological treatment or 'talking therapies' in particular.

Why have I been invited?

You have been invited to take part in this study because you have recently received a diagnosis of NEAD. It may be that you were either approached by a member of your care team such as your neurologist or psychologist, selected from a waiting list for psychological services, or heard about the study through the NEAD Trust.

Do I have to take part?

No, you do not have to take part in this study. It is up to you to decide whether or not to take part. If, after careful consideration, you do decide to take part, you will be asked to sign a consent form. If you do decide to take part you are still free to withdraw from the study at any time and you do not need to give a reason. Please be assured that the decision not to take part or a decision to withdraw from the study at any time during the research will not affect the standard of care that you receive from the NHS.

What will happen to me if I take part?

If you do decide to take part, we will contact you to arrange a day and time that suits you to meet with the lead researcher (Gillian Fairclough). Before meeting you will be sent one questionnaire through the post. This questionnaire will ask for further details about yourself and your seizures. You will be asked to bring this questionnaire with you when you meet with the researcher. Meetings are likely to take place either at your local hospital, a community setting or another appropriate venue. During the meeting, you will be asked to complete three further

questionnaires asking about your close relationships, your well-being and problems and complaints that people sometimes have. This will take around 15 minutes. We would then like to talk to you about what you feel your treatment needs are and to hear your views about psychological treatment or 'talking therapies'. This will last approximately 30-60 minutes. There are no right or wrong answers, we just want to hear your opinions. With your permission, we would like to audio record our conversation. This is so the conversation can be written up after the meeting, in order for us to conduct research on it. All information that is provided will be kept private and confidential. You will also be compensated £10 to cover your time and costs.

What are the possible disadvantages and risks of taking part?

Some people become upset when talking about their difficulties. We do our best to ensure that people are supported during the research and we will not pressure you to continue if you do not wish to. Please bear in mind that you can withdraw from the research study at any time, even during our meeting and conversation. If, during or after our meeting, you feel that you would like to talk to someone else about how you are feeling, you will be given details of someone whom you can contact.

What are the likely benefits?

There is very little research on the needs and views of people with NEAD, which is why we are conducting this study. An increased awareness of the needs of people with NEAD may enable the NHS to develop better treatments in the future.

Will my taking part in this study be kept confidential?

Yes. Only members of the research team will have access to the audio recording and transcripts of your recording, which will be kept in a locked cabinet at the University of Manchester or on encrypted computers. No one involved in your care will be able to identify who has or has not taken part in the research from the final report. Your names will not be used and no personal information about yourself will be given in the final report. Confidential information would only be shared with other professionals under the circumstances that yourself or someone else was at significant risk of harm, in which case the researcher would usually discuss this with you first.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact the University Research Office on 0161 275 7583 or 0161 275 8093 or by email research-governance@manchester.ac.uk.

What will happen to the results of the research study?

The results of the study will be published as a thesis and submitted for publication. We also plan to send a summary of the research to participants if they wish to receive this. Any information used in the reports will be anonymised.

Who is organising and funding the research?

The research has been organised with the support of the University of Manchester, Sheffield NHS Teaching Hospitals and Salford Royal Hospitals Foundation Trust. It has also been subject to review by the Liverpool East NHS Research Ethics Committee.

Who can I talk to for further information?

Gillian Fairclough (Lead Researcher)

Division of Clinical Psychology

2nd Floor, Zochonis Building

University of Manchester

Brunswick Street

Manchester M13 9PL

Mobile: 07527 598 167

Email: gillian.fairclough@postgrad.manchester.ac.uk

Richard J. Brown (Academic Supervisor)

Division of Clinical Psychology

2nd Floor, Zochonis Building

University of Manchester

Brunswick Street

Manchester M13 9PL

Phone : 0161 306 0400

Email: richard.james.brown@manchester.ac.uk

PLEASE DO NOT HESITATE TO ASK IF YOU HAVE ANY MORE QUESTIONS, EITHER NOW OR LATER

Thank you for reading this information sheet. Please feel free to keep it for future

PLEASE DO NOT HESITATE TO ASK IF YOU HAVE ANY MORE QUESTIONS, EITHER NOW OR LATER

Thank you for reading this information sheet. Please feel free to keep it for future reference.

Appendix 9

Postal Opt-In Form

CONSENT TO CONTACT FOR PARTICIPATION IN RESEARCH

We would like your permission for a member of our research team to contact you about participating in the research study:

Treatment needs of people with Non-Epileptic Attack Disorder

Part One

Do you consent for the research team to contact you to discuss participating in the research study?

Yes ☐

If yes, please complete part 2.

No ☐

If no, thank you for taking the time to complete this form.
Declining to be part of this research study will have no impact on the standard of care you will receive.

Part Two

Please complete the details below for a member of the research team to contact you. All information you provide will be kept confidential and will not be used for any other purpose than to contact you about participating in the research study.

Name:

Address:

Land line:

Mobile:

Email address:

By signing I confirm that I have read and understand this consent-to-contact form. I understand that I am only giving permission for a researcher to contact me about the study and that I can decline to be part of the research if I wish. I understand that this will not affect my care in any way. I hereby give consent to be contacted for the purposes indicated above, within 8 weeks from the date of signing this consent form:

Name (please print)

Signature

Date

Appendix 10

Demographics Questionnaire

DEMOGRAPHICS QUESTIONNAIRE

Please complete this questionnaire, answering all questions as fully as possible. All information collected will be kept confidential. Please bring the completed questionnaire to your meeting.

<i>Part 1: Information about you</i>	
Q1	Which best describes you? Male <input type="checkbox"/> Female <input type="checkbox"/>
Q2	What is your date of birth? ____/____/____
Q3	What is your ethnic group? <div style="margin-left: 20px;"> A: <i>White</i> ↑ British.....<input type="checkbox"/> ↑ Irish.....<input type="checkbox"/> ↑ Any other White background, please state _____ </div> <div style="margin-left: 20px;"> B: <i>Mixed</i> ↑ White and Black Caribbean.....<input type="checkbox"/> ↑ White and Black African.....<input type="checkbox"/> ↑ White and Asian.....<input type="checkbox"/> ↑ Any other mixed background, please state _____ </div> <div style="margin-left: 20px;"> C: <i>Asian or Asian British</i> ↑ Indian.....<input type="checkbox"/> ↑ Pakistani.....<input type="checkbox"/> ↑ Bangladeshi.....<input type="checkbox"/> ↑ Any other Asian background, please state _____ </div> <div style="margin-left: 20px;"> D: <i>Black or Black British</i> ↑ Caribbean.....<input type="checkbox"/> ↑ African.....<input type="checkbox"/> ↑ Any other Black background, please state _____ </div> <div style="margin-left: 20px;"> E: <i>Chinese or other ethnic group</i> ↑ Chinese.....<input type="checkbox"/> ↑ Any other, please state _____ </div>
Q4	What is your marital status? <div style="margin-left: 20px;"> Single (never married).....<input type="checkbox"/> In a relationship, living apart.....<input type="checkbox"/> Living with a partner.....<input type="checkbox"/> Married.....<input type="checkbox"/> Separated.....<input type="checkbox"/> Divorced.....<input type="checkbox"/> Widowed.....<input type="checkbox"/> Other (please specify): _____ </div>

Q5	Which best describes your home: Owned..... <input type="checkbox"/> Council/housing association rented.... <input type="checkbox"/> Privately rented furnished..... <input type="checkbox"/> Privately rented unfurnished..... <input type="checkbox"/> Other (please specify): _____
Q5	Who lives in your household? <i>(You can tick more than one box)</i> I live alone..... <input type="checkbox"/> Spouse/partner..... <input type="checkbox"/> Children..... <input type="checkbox"/> Brothers/sisters..... <input type="checkbox"/> Other relatives..... <input type="checkbox"/> Non-family members..... <input type="checkbox"/> Anyone else (please specify): _____
Q7	What is your employment status? Employed Full Time..... <input type="checkbox"/> Employed Part Time..... <input type="checkbox"/> Self Employed..... <input type="checkbox"/> Student..... <input type="checkbox"/> Unemployed..... <input type="checkbox"/> Looking after home/family..... <input type="checkbox"/> Currently sick/disabled..... <input type="checkbox"/> Other (please specify): _____
Q8	What is your highest qualification? (Please circle number) 1. No formal qualifications 2. GCSE/O-level grade D – G <i>(or equivalent: NVQ 1; GNVQ Foundation; CSE below grade 1; BTEC first or general certificate; RSA Stage I, II and III; City and Guilds part 1)</i> 3. GCSE/O Level Grade A* – C <i>(or equivalent: NVQ 2; GNVQ intermediate; RSA diploma; City and Guilds craft or part II; BTEC first or general diploma)</i> 4. AS or A Levels <i>(or equivalent: NVQ 3; GNVQ advanced; OND, ONC, BTEC National; City and Guilds advanced craft, Part III; RSA advanced diploma)</i> 5. Other Higher Education below Degree Level <i>(HNC, HND, Higher level BTEC, teaching, nursing or other medical qualifications (below degree level), RSA higher diploma)</i> 6. Degree or Degree Equivalent <i>(professional qualifications at degree level; NVQ level 4)</i> 7. Postgraduate, Postgraduate Equivalent or above <i>(Higher degree and postgraduate qualifications, PQSW, Postgraduate diploma and certificates, NVQ level 5, Masters, Doctorates)</i>
Part 2: Information about your seizures	
Q8	At what age did you first experience your non-epileptic attacks? _____ years
Q9	Roughly, when did you receive your diagnosis of Non-Epileptic Attack Disorder (NEAD)? _____ (Month) _____ (Year)
Q10	What length of time passed between your first seizure and receiving your diagnosis of NEAD? _____ (Month) _____ (Year)

Q12	Roughly, how many seizures do you have in a typical month? _____seizures
-----	---

Thank you for taking the time to complete this questionnaire.
Please bring this questionnaire with you when you meet with the researcher.

Appendix 11

Written Consent Form

CONSENT FORM

Project: Treatment Needs of People with Non-Epileptic Attack Disorder
Researchers: Gillian Fairclough, Richard Brown, John Fox, Markus Reuber & Gemma Mercer

Please initial box

1. I confirm that I have read and understood the information sheet dated.....
for the above study and have had the opportunity to ask questions.
2. I understand my participation is voluntary and that I am free to withdraw any
time, without giving any reason, without my medical care or legal rights being
affected.
3. I agree to the interview being audio recorded
4. I agree to the use of anonymised quotes in publications
5. I give permission for the researcher to access my medical records for purposes
relating to the research study
6. I understand that relevant sections of my medical notes and data collected
during the study maybe looked at by responsible individuals from The University
of Manchester, from Regulatory Authorities or from the NHS Trust, where it is
relevant to my taking part in this research. I give permission for these individuals
to have access to my records
7. I agree to take part in the study

☐☐☐☐☐☐☐

If you are happy to participate in this research, please complete and sign the consent form below.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 12

Interview Guide

Interview Guide

1. Perception of NEAD (short introduction to interview)

Aim: Gain an understanding of participants' understanding of NEAD as a condition and what they think of NEAD as a psychological condition

Opening question: What is your understanding of non-epileptic attacks?

Pointers for follow up:

- Feelings towards their diagnosis
- Thoughts/feelings about NEAD as a psychological condition
- What others think about this (e.g. family, friends, neurologist, GP)

2. Perception of treatment needs

Aim: Gain an understanding of participants' perceptions of their treatment needs and any links between this and their perceived prognosis, treatment preferences, the opinions of others and how influential these opinions are

Opening question: What do you feel you need in terms of treatment for your non-epileptic attacks?

Pointers for follow up:

- Perceptions of potential for recovery
- Focus of treatment: e.g. psychological, medication, self help, systemic, support group
- Professional opinions
 - Feelings about this? Followed professional recommendations thus far? Are recommended treatments available?
- Family or friends' opinions
 - Feeling about this? Influential figures?

3. Previous treatment experiences

Aim: Gain an understanding of previous treatment experiences with a specific focus on experiences with talking therapies.

Opening question: What is your past experience/s of talking therapies?

Pointers for follow up:

- Specifically whether they have met with a psychologist, neuropsychologist, psychotherapist or counsellor
- Explore the focus of previous talking therapies
- Perceptions of whether any such treatment has been helpful and why
- Perceptions of whether any such treatment has not met their needs and why

4. Expectations of therapy

Aim: Gain an understanding of expectations of talking therapies, particularly participants' preferences and anticipated benefits of therapy, their understanding of therapy and their openness to therapy as a treatment option.

Opening question: Have you considered talking to someone like a psychologist or therapist about your non-epileptic attacks?

Pointers for follow up:

- Understanding of seeing a therapist
 - Potential areas to cover:
 - i. Understanding of therapy process
 - ii. Focus of therapy
 - iii. Expectation of therapist
 - iv. Perceptions of length of therapy
- Perceived benefits of therapy
- Motivation for engaging with therapy at time of interview
- Presence of ambivalence or resistance. Reasons for this?
- Preference for type of therapy or therapist
- Others' recommendations of therapy. Feelings about this?

Appendix 13

Brief Symptom Inventory

This appendix is supplemented at the back of the dissertation and will be available for the purposes of examination only.

Appendix 14

Trauma Symptom Checklist

TSC-40

How often have you experienced each of the following in the last two months?

0 = Never-----3 = Often

1. Headaches	0	1	2	3
2. Insomnia (trouble getting to sleep)	0	1	2	3
3. Weight loss (without dieting)	0	1	2	3
4. Stomach problems	0	1	2	3
5. Sexual problems	0	1	2	3
6. Feeling isolated from others	0	1	2	3
7. "Flashbacks" (sudden, vivid, distracting memories)	0	1	2	3
8. Restless sleep	0	1	2	3
9. Low sex drive	0	1	2	3
10. Anxiety attacks	0	1	2	3
11. Sexual overactivity	0	1	2	3
12. Loneliness	0	1	2	3
13. Nightmares	0	1	2	3
14. "Spacing out" (going away in your mind)	0	1	2	3
15. Sadness	0	1	2	3
16. Dizziness	0	1	2	3
17. Not feeling satisfied with your sex life	0	1	2	3
18. Trouble controlling your temper	0	1	2	3
19. Waking up early in the morning and can't get back to sleep	0	1	2	3
20. Uncontrollable crying	0	1	2	3
21. Fear of men	0	1	2	3
22. Not feeling rested in the morning	0	1	2	3
23. Having sex that you didn't enjoy	0	1	2	3
24. Trouble getting along with others	0	1	2	3
25. Memory problems	0	1	2	3

26. Desire to physically hurt yourself	0	1	2	3
27. Fear of women	0	1	2	3
28. Waking up in the middle of the night	0	1	2	3
29. Bad thoughts or feelings during sex	0	1	2	3
30. Passing out	0	1	2	3
31. Feeling that things are "unreal"	0	1	2	3
32. Unnecessary or over-frequent washing	0	1	2	3
33. Feelings of inferiority	0	1	2	3
34. Feeling tense all the time	0	1	2	3
35. Being confused about your sexual feelings	0	1	2	3
36. Desire to physically hurt others	0	1	2	3
37. Feelings of guilt	0	1	2	3
38. Feelings that you are not always in your body	0	1	2	3
39. Having trouble breathing	0	1	2	3
40. Sexual feelings when you shouldn't have them	0	1	2	3

Thank you for taking the time to complete this questionnaire

Appendix 15

Extract of coding

Appendix 15: Extract of coding

Memos/Notes	Transcript	Coding
	Mm. And you said also that you were feeling upset as well, can you, can you say more about that as well?	
<p>Hopes for a resolution have not been met and she links this with the upset referred to.</p> <p>This is similar to P4 describing the need for a strategic plan.</p> <p>'Instead' reinforces that her expectations were not met. This seems to fit with her descriptions of being 'left' by services earlier.</p>	<p>'Cause I thought that we'd reach an end and get something done, so.</p> <p>'This is what it is, this is what we can do', and then it'd be sorted. And instead it was, well this is what it is, and that was it.</p>	<p>Upset. Expectations not met. Expectations for resolution. Expectations for intervention.</p> <p>Need for definite answers. Need for intervention. Recovery possible. ? Lack of action halting recovery. Services: expectations not met.</p> <p>No action following diagnosis. ? Left by services</p>
	Mm, mm. And so what did you hope that might have happened there that didn't happen?	
<p>Self aware of what she is saying during interview.</p> <p>It seems she views epilepsy as providing a definite answer and plan, NEAD on the other hand is leaving her feeling lost – is this something to do with her viewing psychological conditions as less legitimate or due to the wait.</p> <p>It seems she needs to feel that she is moving towards resolving her seizures, whereas there is an element of feeling 'stuck' about this.</p>	<p>In some ways, and I know it sounds awful, I wish they had turned round and said "Yeah, it is definitely epilepsy, this is what we'll do" and we've got an aim and a goal. But now we've not. It's like, 'you've got this NEAD now'. There's not been no aim, there's not been no goal.</p>	<p>Need for definitive answers. ? NEAD feels uncertain. Desire for action post-diagnosis.</p> <p>Need for direction.</p> <p>Post diagnosis: lost. Aimless.</p> <p>Post diagnosis: lack of direction. Services: not met her needs. Need to move forward.</p>
	Mm. And how does it feel not to have an aim and a goal?	
Control seems an important theme for this participant and has been discussed by others in relation to their seizures.	It makes you feel pretty useless and defenceless. You've no control on it.	<p>Lack of a goal renders her useless.</p> <p>Vulnerable without control.</p>
	Right. And I'm just interested in understanding more what you mean by defenceless?	

<p>Control seems to be an important part of her life.</p> <p>It seems that she does want to have agency over the condition however it seems she feels she can't do this on her own. ? possibly why she is looking to services.</p>	<p>Cos I'm, when I go through life, every day is an aim and a goal. I've a good day, do this, we'll do that, you know, and then at end of your day usually something good comes out of it. But with me not having the control, that's why I feel defenceless. Because no matter what I do I've no, for this situation there's no end, and I can't do anything to make it just finish.</p>	<p>Needs control.</p> <p>Values being productive.</p> <p>Feels better in control.</p> <p>Vulnerable without control.</p> <p>Powerless to resolve her situation.</p> <p>Hopeless.</p> <p>No agency over her condition.</p> <p>No control over recovery.</p>
	<p>Mm. And is that a feeling that's, that came around when you had the change of diagnosis?</p>	
<p>Epilepsy seen as concrete but PNES is not – this links with her uncertainties about her diagnosis.</p> <p>Feels helpless that she doesn't know how to move forward with the condition.</p>	<p>I think so because, like I say, if they'd have turned round and saying that "It's definitely epilepsy and this is what we'll do and we've a plan." And then I've got some control as well, rather than being told "No, you've got this." And then I'm sat at home, and what do I do with it?</p>	<p>Post-diagnosis: loss of control.</p> <p>Perception her situation would be better with epilepsy.</p> <p>Desired a definite plan.</p> <p>Need for control.</p> <p>? Denied control due to diagnosis.</p> <p>Diagnosis lacked follow up.</p> <p>Feels helpless.</p>
	<p>Mm, yeah. And so, I guess I'm interested in, in knowing whether you feel that, that this is the right diagnosis that they've given you, that this is the right understanding of your difficulties?</p>	
<p>She is uncertain but seems to be going along with professional opinion.</p>	<p>I don't know, to be honest. They should know whether it's right or not.</p>	<p>Uncertain about diagnosis.</p> <p>Defers to professional's expertise.</p>
	<p>What do you feel about it?</p>	

	(Pause) To be honest, I don't know, don't know.	Uncertainty about diagnosis.
	And if you had a hunch would you, do you think that this is the best explanation at the moment?	
<p>This has come up before with other participants.</p> <p>Is there something about going along with the diagnosis as it is the only option?</p> <p>The alternate explanation she seems to be querying is epilepsy and this is similar to other participants – is this preventing her agreeing with the diagnosis.</p>	<p>I think it's the only explanation.</p> <p>Maybe not the best but the only.</p> <p>Because if I'd have been in this position, like I say, when I was younger, and tests had been done, would it still have the same outcome or would they say "Yeah, it's epilepsy?"</p>	<p>Diagnosis as only explanation.</p> <p>Diagnosis not best explanation. ? Diagnosis only thing on offer.</p> <p>Questions reliability of diagnosis.</p> <p>Alternative explanation as epilepsy.</p>
	Mm. I'm just wondering do you, do you feel there might be a physical reason for your, for your seizures?	
<p>Has experienced injuries as a result of her condition – does this link with her loss of independence/ feelings of vulnerability.</p> <p>She seems to feel the professional is perceiving her as unstable, P4 had a similar experience.</p>	<p>(Pause) I don't know. One of the first things that were said to me when I went for a first appointment with the neurologist was, I sat down and explained all the symptoms and what had been happening, cause I'd had to go into hospital twice because of injuries I'd got from them and, it's not the same one I've got now, but he turned round to me and said "Well what do you think it is? Do you think it's a brain tumour?" Now that sounds like a question for someone who's a bit unstable or something, you know, it's not, it don't sound like</p>	<p>Uncertain about cause.</p> <p>Sought help from services for seizures.</p> <p>Past acute medical care.</p> <p>Injured by seizures.</p> <p>Change in professionals.</p> <p>Professionals questioned her beliefs in illness.</p> <p>Professional: being viewed as unstable.</p>

The use of ordinary here is interesting infers she thought he saw her as different.	the type of question you'd ask an ordinary everyday person.	? viewed as different by professionals.
	Mm. So how did, how did you make sense of that? Why do you think he asked you that?	
Is this linked to the legitimacy of the illness and not being believed as she discussed.	I felt that he thought I were being a timewaster.	Not taken seriously by professionals. ? Not 'genuine'.
	Right. And kind of how did that affect you, that you thought he was maybe thinking you were a timewaster?	
Participants have also discussed similar feelings of disengagement from services following feelings of being a fraud or not being taken seriously – important for implications.	It makes you feel just like not bothering with it. Why seek help for, from someone who's just gonna come out with something like that? And you don't know what the hell's going on yourself.	Not taken seriously: disengaging. ? Resentful of professionals. No knowledge of condition. ? Annoyed at not knowing.
	Mm. And so how would you have preferred him to have been with you?	
	Well straight but not facetious.	Professionals: values straightness.
	OK, yeah. So that's how it felt, that he was being facetious?	
	Yeah. I don't think he'd have said that if me husband were with me.	Professionals: not taking her seriously.
	Right. Why do you think he wouldn't have said it if your husband had been with you?	
? feeling that people do not take her seriously when she compares herself to others.	I just don't.	