



Written accounts of living with psychogenic nonepileptic seizures: A thematic analysis



Gregg H. Rawlings^{a,*}, Ian Brown^b, Brendan Stone^c, Markus Reuber^a

^a Academic Neurology Unit, University of Sheffield, UK

^b Department of Psychology, University of Sheffield, UK

^c School of English, University of Sheffield, UK

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ABSTRACT

Purpose: Qualitative studies examining lived experiences of psychogenic nonepileptic seizures (PNES) have predominantly relied on datasets collected using clinical or research interviews. This study pursued a different approach by investigating individuals' written accounts of their condition.

Methods: Participants (n = 19) were recruited from membership-led organisations for individuals living with seizures and from a United Kingdom hospital. Participants were instructed to produce four pieces of writing: 1) about their thoughts and feelings about their condition; 2) a letter to their condition; 3) a letter to their younger self; and 4) about a personal value. All writings were analysed using thematic analysis.

Results: Six main-themes emerged from the data. Theme 1: 'living with PNES' demonstrated that all participants presented the condition as having a debilitating effect. Theme 2: 'Emotions' revealed that individuals were struggling with anxiety, low mood and self-worth. Theme 3: 'Seizure symptoms' showed variability was a prominent feature in the description of ictal events. Theme 4: 'Treatment and outcomes' demonstrated that individual's perception of diagnosis and therapy differed greatly. Theme 5: 'Causation and development' revealed that the majority of participants spontaneously reported experiencing a traumatic event in the past. Theme 6: 'Lack of understanding' by themselves, the public and healthcare professionals appeared to pose considerable challenges to participants.

Conclusions: Qualitative research has an important role to play for improving our understanding of PNES. The findings contribute to the literature by highlighting the nature of stigma that people with PNES experience, and also their proneness to demonstrate problems with self-worth.

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1. Introduction

Psychogenic nonepileptic seizures (PNES) are one of the most important differential diagnoses of epilepsy. PNES superficially resemble epileptic seizures, but are not associated with epileptiform activity. Instead, PNES are considered to have a psychological basis and can be best understood as a dissociative response to distressing stimuli [1,2]. Approximately one in five patients referred to epilepsy clinics will have PNES [3,4].

Most research investigating the psychological aspects of PNES has utilised quantitative methodologies [5]. These studies have

demonstrated that PNES are intra- and inter-individually heterogeneous in terms of clinical manifestations [6,7], aetiology [8], comorbidities [1], socioeconomic and demographic variables [4], personalities [9], psychological and emotional profiles [10], coping styles [11,12], response to treatments [13,14], and prognosis [15].

Whilst quantitative studies have provided many insights into the characteristics of PNES, they are at risk of oversimplifying the complexities and idiosyncrasies of how the condition impacts individual patients. For example, participants typically have to respond to questions using pre-defined categorical answers and are unable to clarify or communicate the finer subtleties and variations of their experiences. Qualitative methodologies on the other hand, allow researchers to ask more general and open-ended questions. These approaches encourage individuals to tell their story, in their own words, which means that responses are more likely to reflect the challenges and concerns they experience as most important. Whilst this means that the data collected can be

* Corresponding author at: Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF, UK.

E-mail addresses: grawlings1@sheffield.ac.uk (G.H. Rawlings), ian.brown@sheffield.ac.uk (I. Brown), b.stone@sheffield.ac.uk (B. Stone), m.reuber@sheffield.ac.uk (M. Reuber).

more difficult and time consuming to interpret or categorise, it is fine-grained and rich in detail.

How we experience and narrate an event is a highly personal and complex process, which is affected by a range of influences including cultural and psychosocial factors [16]. It follows that the use of different methodologies to analyse and collect data to investigate subjective accounts are likely to produce the best possible insights into a problem. However, a recent systematic synthesis of the qualitative literature examining the phenomenology of PNES reported that, whilst a range of different qualitative analytic approaches have been used, studies to date have predominately relied on datasets collected using clinical or research interviews [5].

The current study pursues a different approach of data collection and aims to deepen our understanding of living with PNES through the thematic analysis of people's writing about their condition. Writing has been considered an individual act allowing for private consideration, exploration and expression of thoughts and feelings [17]. Compared to the more immediate nature of spoken responses, writing gives individuals more opportunity for reflection and control over their account. The same research design and methodology has been used to investigate the subjective experience of living with epilepsy. This produced revealing insights into how people with epilepsy manage the condition and highlighted some important considerations for clinical practice [18].

2. Methods

2.1. Participants

Participants were primarily recruited through membership-led organisations for individuals experiencing seizures (see acknowledgements for the list of organisations). Participants recruited from such organisations self-declared that they had received a diagnosis of PNES and that they did not experience epileptic seizures as well. Participants were also approached consecutively and recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield (United Kingdom, UK). Recruitment took place between October 2015 and November 2016. The North of Scotland Research Ethics Committee granted ethical approval for this study (15/NS/0078). Participants were included if they were over the age of 18 years, had a diagnosis of PNES (participants with comorbid epilepsy and PNES (either self-declared or proven) were excluded), and were able to complete a demographic and clinical questionnaire without help. The diagnosis of individuals recruited at the Royal Hallamshire Hospital was confirmed by review of their hospital records. When possible, confirmation of the self-reported diagnoses of participants recruited through membership-led organisations was sought from their General Practitioner.

2.2. Data collection

This dataset was collected in the context of a randomised control trial investigating the effects of an expressive writing intervention for individuals with seizure disorders. The current study is based exclusively on data from participants with PNES allocated to the *intervention* group. A total of 19 individuals were included, which is the number of participants recruited to the intervention at the time that the current study was undertaken. Participants recruited from membership-led organisations replied to an advert for a study of a writing intervention designed to help individuals with seizure disorders. Potential participants then contacted G.R. who gained written informed consent and provided access to an online form allowing participants to complete the self-

report measures. Participants recruited from outpatient neurology clinics were sent a participant information sheet at least 48 h before their appointment with a Consultant Neurologist. On the day of their appointment, individuals were approached and invited to take part in the study. Those who gave written consent were asked to complete a set of self-report measures.

All participants were then given four writing booklets. Each booklet contained writing instructions, space for writing (four A4 sheets of lined paper) and a link to a website for those participants preferring typing to handwriting. Participants were asked to produce four pieces of writing: 1) their very deepest thoughts and feelings about their condition [19]; 2) a letter to their condition [17]; 3) a letter to their younger self [20]; and 4) about a personal value and why it is important [21]. The topics had been set based on previous studies of writing therapies in other patient and non-clinical groups. Participants were asked to write for at least 20 min per question, at home and in private.

2.3. Self-report measures

Participants completed a demographic questionnaire that recorded their age, gender, employment status and years of education. Participants were also asked how long they had experienced PNES and the date of their last seizure. To investigate the effectiveness of the writing intervention, outcome measures were taken at baseline, one- and three-month follow-up. For this purpose, participants' health-related quality of life (HRQoL) was investigated using the NEWQOL-6D [22]. This is a six-item HRQoL measure specifically developed for individuals with seizures. A higher score represents a better HRQoL (0.96–0.34). The Generalised Anxiety Disorder (GAD-7) was used to measure anxiety [23]. This is a seven-item scale used as a screening tool and severity measure of mild (score of 5–9), moderate (10–14) and severe anxiety (>15). The six-item Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) was used to screen for likely major depression [24]. Scoring above 15 suggests a current major depressive episode. Seizure frequency and severity were investigated using the Liverpool Seizure Severity Scale questionnaire (LSSS-3) [25]. This is scored from 0 to 100 with a higher score representing greater seizure severity. The baseline scores have been reported in the current study to provide some information about the group of individuals sampled here – this allows readers to relate our findings to the patient populations they treat or study.

2.4. Data-analysis

The qualitative approach was guided by the methodology of thematic analysis [26]. This method was based on a mixed inductive (themes were grounded in the data) and theoretical approach (themes were influenced by the existing literature, primarily from the themes identified in a systematic synthesis of qualitative research into PNES [5]). Participants' answers to each of the four questions were read separately, but as individuals expanded on experiences mentioned in their initial writings in later sessions it was decided that their written responses to all four topic prompts would be considered together in the analysis. The data was analysed in six steps (Table 1). In the results section, the main themes are presented in the order in which participants often structured their written accounts. Participants quotes are represented by "".

Measures were taken to ensure the trustworthiness of our findings, including expert checking and working reflexively [27]. Participants were informed that they should write for themselves as they would not be contacted about what they wrote. Whilst this meant that individuals may have felt that they could have been

Table 1
Stages of thematic analysis.

Stages	Action(s)
1	To become familiar with the content of narratives, G.R. repeatedly read all participants narratives. At this stage and throughout, G.R. aimed to work reflectively taking note of any impressions and reflections on the margin and in a private notepad.
2	G.R. imported and extracted, into NVivo, initial codes. This was a timely and iterative process that involved having to go back through narratives to re-code as new codes emerged.
3	G.R. compared and collated codes to create main and sub-themes.
4	Reviewed the themes and codes to define sub-themes. It was at this stage that the themes were shared and discussed between the authors allowing for changes and clarification. This was repeated until a general consensus was reached for all of the themes. M.R and I.B are currently involved in the clinical care of patients with PNES, and have previously published studies investigating seizure disorders. B.S has extensive experience of qualitatively analysing individuals' written accounts of living with mental health problems. Thematic saturation was not possible as participants were not directed in their narratives and so they could choose to write about anything. However, all narratives were read one final time to make sure no more themes emerged.
5	Further refinement of sub-themes, assigning clear titles and definitions.
6	Writing the report, making the explanation of themes and sub-themes coherent.

more honest and open, we were unable to ask participants to clarify or check the analysis (member checking).

3. Results

The writings from 19 participants (three males) were analysed. Four participants were recruited from outpatient clinics. Thirteen individuals were from the UK, five from the United States, and one was from Holland. The median score of participants on the measure of HRQoL was 0.67 and seizure severity 52.5. In total, 63% of individuals scored above the cut-off for likely major depression. 31.6% of participants scored above the cut-off for mild-, 5.3% for moderate-, and 36.8% for severe-anxiety (see Table 2 for further demographic and clinical details).

Six main themes and 26 subthemes emerged from the data. The six themes reflected accounts of: (i) living with PNES, (ii) emotions, (iii) seizure symptoms, (iv) treatment and outcomes, (v) causation and development, and (vi) lack of understanding by themselves, others, and healthcare professionals (HCPs) (Table 3). A thematic map illustrating links between the themes has been included as a supplement (Figure 1).

3.1. Theme 1: living with PNES

3.1.1. Daily life

It was clear from the very outset that PNES had a profound impact on individuals. Twelve participants began the first writing

session with an emotional expression: “*I hate this condition*” (Q1). Thirteen individuals also finished their writing sessions in a negative tone (Q2). It appeared that every day was a great burden and struggle; nine participants explained that their seizures had “ruined” or “destroyed” their lives. Individuals explained that they are unable to “function”, they no longer felt “normal”, and PNES has “stopped” or “crashed” their lives. Tiredness appeared to be a daily occurrence, which was attributed to a range of causes such as, lack of sleep and frequent seizures causing “relentless fatigue” (Q3).

3.1.2. Coping

Individuals did not try to present themselves as coping well or to hide the fact that they were suffering (Q4–5). Only five participants explained that they are coping with some aspects of the condition. Others seemed hopeless or found it difficult to fight it: “*I haven't got it in me any more to rant and rave . . . I suppose I have stopped fighting*”. Four of these participants explained that they would not let PNES “win” or “destroy” them; three appeared to develop this attitude through therapy, while the other explained “*now my seizures are more controlled. . . I don't feel that they control me anymore*”.

3.1.3. Isolation

Eight participants expressed concerns or fears about leaving the house (Q6). It seemed that this feeling was most common soon after the development of seizures. One participant explained this was because they had lost the confidence to go to places on their

Table 2
Clinical and demographic information of participants.

P	Age	Gender	Years in Education	Employment	No. of seizures in the last 4 weeks	Years since onset	Diagnosis confirmed
1	46	F	13	Unemployed	224	5	Y
2	44	F	18	Disability	Up to 20 a day	8	Y
3	57	F	10	Disability	30	7	Y
4	69	M	20	Pension	7	1	N
5	26	F	16	Disability	2	1	N
6	54	F	12	Unemployed	10–15	3	Y
7	27	F	17	Employed	1	1	N
8	60	F	–	Employed	4	8	Y
9	52	F	19	Employed	39	7	Y
10	35	F	15	Employed	0 (3 a year)	17	N
11	31	F	18	Self-employed	30+	9	Y
12	26	F	16	Disability	35	3	Y
13	20	F	9	Disability	50+	3	Y
14	43	F	–	College	120	–	Y
15	46	M	11	Disability	9	4	Y
16	31	F	17	Employed	1	22	N
17	31	F	17	Disability	340	6	N
18	28	F	16	Employed	4	5	Y
19	42	M	–	Disability	20	3	N
Median/%	42	F: 84%	16		20	5	Y: 63%

P = Participant, F = Female, M = Male, Y = Yes, N = No.

Table 3
Emergent main themes, sub-themes and illustrative quotes (Q).

Main-theme	Sub-theme	Illustrative quote
Living with PNES	Daily life	"I hate my seizures, they ruin my life" (Q1); "I am a different person. I am weak, fat and useless" (Q2); "I can't get out of bed because I am cluster seizing and the tiredness from them is all consuming" (Q3)
	Coping	"I just need some help" (Q4); "I hate my seizures, my mental illness I can cope with, but being worried all time if I'm going to have a seizure if I go anywhere which I usually do is unbearable" (Q5)
	Isolation	"I was now having about 5/6 fits a day and was so scared of leaving the house." (Q6)
	Loss	"I don't feel like the husband and father I use to be. I'm not able to do as many fun things as I use to with my kids and it hurts them and me when I see them with that dejected look when I'm so tired after a seizure that I can't move" (Q7)
	Stigma	"Not to mention the stigma of the disease. How people freak out and often yell at us when we have a seizure. Do you yell at people who have cancer or heart disease? What gives them the right to judge me" (Q8)
	Friends and family	"I think I have gotten through my condition a lot faster and made a vast improvement due to my family and friends support and I no doubt would not have been able to recover so well without my husband by my side who helped log dissociative episodes and inform my neuro-psychologists of my different personas when disassociating" (Q9)
Emotions	Depression	"... happiness. I struggle with this because so much has been taken away from me" (Q10); "Please tell others how you feel, don't bottle it up like I did and then had 5 suicide attempts... an emotional breakdown" (Q11)
	Anxiety	"Now I have something called seizures. I found out that they might have something to do with all the worrying over so many years" (Q12)
	Self worth	"I hate my seizures, but I hate myself more for having them" (Q13)
	Managing emotions	"It took me way to many years of hiding and burying all my emotions until it left me with very poor health" (Q14); "I was mostly un-aware of the trauma my life had brought and I was very clever at managing my thoughts and emotions of the things I had remembered, they were in lovely neat little packages, packed in pretty boxes in the back of my mind and now they are overflowing, lids a-jar or missing, some boxes seem broken and need replacing and my store room is a mess!!!!" (Q15)
Seizure symptoms	Triggers	"I don't know what is going to trigger anything, what will happen next, when, on what day. I can't plan anything; When I feel so overwhelmed and the tremors start I remember I can control my thoughts, I am in control, not my mind." (Q16)
	Warnings	"My friends all said I've been sober and fine then either start staring or being weird then fall to the floor or just drop to the floor!" (Q17)
	Going into a seizure	"... taken out of my seizure" (Q18); "...I dealt with the big traumatic events I can talk about them without going into seizure" (Q19); I often think I am back in that hell hole, having just relived the whole thing again whilst in seizure" (Q20)
	Seizure experiences	"My thoughts feel mushy, like I'm not sure what is real and what I dreamt. If I concentrate I get pains in my head. I don't get blurred vision it is more I like get more vision" (Q21); When I used to be unconscious I thought that was bad but since Christmas I am now awake whilst I have them, I relive everything whilst talking others through the whole thing even though I'm not aware. (Q22)
	Fear	"I relive everything during seizures, when I wake and think I am still there I am terrified and my body hurts like everything happened all over again" (Q23)
Treatment and outcomes	Before diagnosis	"I did not back down though with trying to get a diagnosis" (Q24); "Seven years it took for you to be diagnosed properly" (Q25)
	Diagnosis	"I was happy to have a diagnosis but I was also devastated. There was no magic pill or surgery that would help me" (Q26); "I was diagnosed and within two minutes was out of the clinic room after having been discharged as there was nothing they could do" (Q27)
	Reaction	"I'm not yet convinced that there is no physical link" (Q28)
	Therapy	"I live in one of the biggest cities in the US and there are no doctors who specialise in this field. What hopes does that give us" (Q29); "I have had so much different therapy over the last 7 years" (Q30)
	Outcome	"I can have a future" (Q31); "The longer the seizures go on for the more angry, depressed and down I feel. I don't see no light at the end of the tunnel" (Q32); "I can control you by breathing then there is light at the end of the tunnel eventually" (Q33)
Causation and development	Trauma	"What my aunty did really affected me and still does today. I can't help blame myself for her death. Did I make her stressed? Did I worry or scare her too much/often? Should I have opened up to her the way I did"(Q34); "No-one can go through that and come out mentally intact"(Q35)
	Development	"... years of heartache and something that will cause problems, huge problems... one day it will catch up with you and you will have a condition" (Q36)
	Other conditions	"I still am trying to find another diagnosis as I have many other confirmed health problems... they are wondering if it may be a result of something underlying e.g. Lyme disease." (Q37)
Lack of understanding	Of participants	"Truth be known, I don't fully understand why I seize" (Q38); "I hate what you are called. Pseudo, psychogenic, NON epileptic. The name alone suggests fake" (Q39)
	Of others Of healthcare professionals	"Well my husband has not got a clue... I swear he thinks I just have a cold sometimes or the flu" (Q40) "I am a nurse and worked on a neuroscience ward. We have a participant who's mum has pseudo seizures and the nurses always mock her or say she is weird and fakes seizures – these are professionals and even they don't understand it." (Q41)

own; "worried about having fits in public... what people might think... crossing the road, people mugging me... or worse". Participants explained that family members also thought that they should not leave the house. Constantly having to be with someone made individuals feel like "I am no longer a strong independent person" or "trapped".

3.1.4. Loss

Participants complained of being unable to drive, go on holiday and exercise. Individuals described having lost their "freedom",

home, "dignity", and "independence" (Q7). Not being able to work because of the health-risks associated with their seizures or they were too tired had a major impact. Work was referred to as a "passion". Both of the two men of working age expressed frustration about no longer being able to work or the "breadwinner".

3.1.5. Stigma

Twelve individuals reported feeling discriminated against by others due to their condition. Not only did participants experience

the stigma associated with having a seizure disorder, they felt discriminated against because they had been diagnosed with a mental condition (Q8). Participants explained that they were “ashamed” of their condition, “scared” and “embarrassed” of what other people might think about them. Individuals did not appear to keep their condition a secret; in fact, they would discuss their frustration that not enough people know about PNES.

3.1.6. Friends and family

Friends and family were a major source of support (Q9). They were described as making it “bearable”, caring and “a rock”. PNES clearly had a negative impact on individuals’ social support. Family members were described as not being sure how much they are able to share with participants because of “fear of tipping me over the edge”. PNES played “havoc” with social lives, for instance, participants felt guilty because they were unable to be a “supportive friend”.

3.2. Theme 2: emotions

3.2.1. Depression

It was clear that participants were struggling with low mood (Q11). This was often perceived as a reaction to developing and experiencing PNES. However, individuals also reported a history of self-harm (n = 3) and/or suicide attempts (n = 2) suggesting that, at least in some cases, depression preceded the manifestation of seizures (Q12).

3.2.2. Anxiety

Individuals would describe “dealing” with “high levels” of stress. This appeared to be a long-term characteristic and/or it was associated with developing PNES: “It’s not the anxiety that caused PNES, the PNES caused the anxiety”. Participants identified that stress is a perpetuating factor of their PNES: “. . . now it’s the everyday stress that keeps my condition going”.

3.2.3. Self-worth

Individuals recurrently indicated a lack of self-compassion: “loser, just pull yourself together”. Participants described themselves as feeling “weak”, “useless”, “pathetic” and a “waste of space and money” (Q13). Three people who had received psychological support, however, described that they learned to explore their “own self worth” and realised that “I am indeed a person in my own right, a very intelligent one”.

3.2.4. Managing emotions

Eight participants discussed processing their emotions. This was described as being “hid”, “buried”, “bottled” or “shut down”. Participants’ reasons for managing their emotions like this varied, for instance, their emotions were “overwhelming”, “harmful”, there was no one to tell them to, and they find it “hard” to communicate what they are feeling; one participant explicitly stated that this was linked to her symptoms (Q14). Following the onset of PNES, it appeared that participants struggled to “regulate” their emotions, for instance, individuals reported now being quickly moved to anger or tears (Q15).

3.3. Theme 3: seizure symptoms

3.3.1. Triggers

Nine individuals described triggers of their seizures. The most common symptoms were exhaustion, tiredness and anxiety. This was discussed as a negative cycle as seizures would make participants fatigued or stressed resulting in more seizures. Individuals explained that their seizures were tied to their emotions and so they had to be constantly aware of their “moods

and feelings, and hormones”. Triggers could also be more mundane (i.e. drinking a cup of tea) or relaxing activities. Triggers seemed to be related to gaining control (Q16).

3.3.2. Warnings

Warning signs were not experienced by all the participants and did not always precede their seizures. Individuals explained that sometimes they experienced warning such as, “feeling weird” or “tremors”, while at other times, there were no symptoms (Q17). Warnings were discussed as being “key” in helping participants to have some control.

3.3.3. “Going into a seizure”

By instructing participants to write a letter to their seizures as a separate entity in session two, we will undoubtedly have encouraged participants to consider their seizures as having agency (acting independently). However, three participants also conceptualised their seizures as an external agent impacting up on them in the other writing sessions. Nevertheless, individuals depicted their seizures as a space or place that they enter, and as an event in which the person experiencing the PNES retained agency: “Emergency Medical Technicians have punched me in the chest to bring me out of a seizure” (Q18–20).

3.3.4. Seizure experience

Seizure frequency varied greatly between individuals from four in a year to 20 in one day. For example, one participant explained that, following their first seizure, they started “like a storm” whilst another pointed out that they only experience seizures intermittently. Seizures were reported as happening as isolated episodes or as a “cluster”. The longest reported seizure was over two hours.

Seven individuals described their levels of consciousness during PNES, revealing both inter and intra-variability (Q21–22). Participants explained that they “blacked out” or were “unconscious” and had woken up unsure what had happened. Others described that they would drift “in and out of consciousness” while some reported being “awake” during the events. Participants also explained that they were “paralysed” during their seizures: “completely aware of the conversation but I couldn’t respond”, while others did not expand on an event saying they had “switched off”.

Seizure symptoms listed by participants varied and included “panic”, “slurred speech”, falling to the floor, not being able to stand properly, feeling “funny” and “dizzy”. Following a seizure, participants also reported being in physical pain such as, experiencing “headaches”, “stiff”, cramping or “being tired”. Mental symptoms were described, such as feeling “groggy”, confused and having a “hard time thinking”.

3.3.5. Fear

Participants described being afraid because they did not know why their seizures were happening nor when they would end, and were constantly scared of triggers or of their next seizure. The seizure itself was also associated with fear. Seizures were described as “by far the scariest experience of my life” (Q23).

3.4. Theme 4: treatment and outcomes

3.4.1. Before diagnosis

Four individuals described discounting their first symptoms associated with PNES, for instance, thinking that they were “faints” or a result of lack of sleep. It was not until their episodes happened during the daytime or disrupted mundane activities that they decided to take their symptoms more seriously. A long duration between symptom manifestation and diagnosis was reported (Q24–25). During this time, participants described undergoing a range of tests and investigations. As these tests kept on coming

back as normal, this period was associated with feelings of frustration, “a nightmare”, and a great deal of worry.

3.4.2. Diagnosis

Individuals reacted to receiving the diagnosis in different ways. Some explained that it was a positive event finding out that they did not have epilepsy (two individuals were at first diagnosed with epilepsy). However, it was a disappointment that there was no quick fix (Q26).

Getting a “name” was important; it made participants feel like they have “got one over on it”. Having said that, getting a label for their problem also had negative consequences, as once participants had been told that their seizures were “associated with stress”, HCPs were described as being less likely to take them or their symptoms seriously. It was clear individuals felt that they could have received more support and information when the diagnosis was first communicated to them (Q26–27). Getting diagnosed had consequences on seizure frequency. One participant explained that her seizures “almost stopped after diagnosis”, whilst another explained that “it got worse after the diagnosis, to the point it is controlling my life”.

3.4.3. Reaction

Six individuals appeared to reject the psychological link, either outright (Q28), or they seemed to demonstrate resistance in the way they described their condition: “It is believed that they are connected to stress and panic”. Five individuals passively resisted the diagnosis by asking for more tests. Rejecting the diagnosis appeared to be a source of tension between the participant and HCPs as individuals explained feeling: “lost”, “left to fend for myself” and “unheard”.

3.4.4. Therapy

Finding and securing access to psychological or specialised care was difficult (Q29). Participants reported having received different types of therapeutic support (Q30). Attitudes towards therapy was mixed; one participant explained that he “finds therapy very patronising”, while another has found therapy “supportive”.

Participants described being hesitant about therapy because they did not “trust” therapists, would not feel comfortable telling their therapist all their innermost thoughts, did not think re-living traumatic experiences would help, and found it difficult to “open up about myself to strangers to let them in” – however, after doing so, this individual explained “I took strength from the fact I was comfortable enough to talk openly. I made me feel better. It felt good”.

A range of benefits of therapy were reported: management skills to cope with stress and seizure warning signs, grounding techniques, becoming more “assertive”; having more ‘control’ over their life and seizures, gaining insight into their emotions, “dealing” with the traumatic event and seizure reduction. Five individuals did not find therapy helpful, they explained feeling “let down”, “lonely”, and were not receiving the “support” that they thought they needed.

3.4.5. Outcome

The timeline of PNES varied. Seizures were described as becoming worse over time, a catalyst for a decline in health overall, as having become “much more controlled”, or fluctuated over time. Expectations were also mixed. Participants explained that their seizures could be cured or controlled; one participant explained that she is “determined to be seizure free in a couple of months”. Participants appeared to describe PNES as something that they are going “through” and that they need to “recover” from (Q31). Other participants seemed to begrudgingly accept that seizures would always be a “part” of their life, but hopefully, a “smaller part”.

This seemed to be related to seizure frequency and how long participants have experienced PNES (Q32–33).

3.5. Theme 5: causation and development

3.5.1. Trauma

Despite the fact that participants were asked to write about their experiences of living with their condition, 16/19 participants spontaneously reported a past trauma. Traumas included past-abuse (sexual, mental and physical abuse), death of a loved one, surgery, clinical depression, and bullying whilst at school. Participants choose to focus on their trauma explaining that it is still affecting them (Q34), or that these events were a contributing factor to developing PNES (Q35).

3.5.2. Development

Thirteen narratives mentioned other factors predisposing participants to the development of PNES. For example, individuals would describe themselves as doing “far too much for other people” or going to their “limits to help people”. Some participants made an explicit association between life events and PNES (Q36).

3.5.3. Other conditions

Nine participants described having other medical diagnoses. Individuals would often perceive PNES as connected to their other disorders, or they mentioned other medical problems as evidence that there maybe another cause of their seizures (Q37).

3.6. Theme 6: lack of understanding

3.6.1. Participants’ understanding

Individuals discussed their lack of understanding of their condition (Q38). This seemed to be unrelated to how long they had experienced PNES. Participants described feeling “angry all of the time” that they do not understand their condition, or that they struggle to understand that it is “mainly psychological as I am normal and don’t have any mental health issues”. The fact that PNES can be called by different names appeared to add to the confusion (Q39). Given their lack of understanding, individuals discussed their difficulties with explaining their condition to others.

3.6.2. Others’ (friends, family and public) understanding

When participants attempted to explain the condition to others, they reported that people often think that they are “a freak or faking it”, and “that you are either making it up or it isn’t a real condition”. Participants reported that people just do not understand how much it affects their life, or how much “pain” it can cause (Q40).

3.6.3. HCPs’ understanding

Fourteen participants described the lack of “understanding”, “awareness”, “interest” and “support” from HCPs. Paramedics and HCPs in emergency departments were described as the worst offenders. HCPs were reported as not wanting to “listen”, “show a great deal of care”, or not taking into consideration what the participant was telling them. HCPs were described as accusing participants of “faking” or “refused to acknowledge” their seizures (Q41). This was a major source of friction between HCPs and participants. Participants wrote about going to doctors for support and care and yet they have been “failed”, made to be felt “worthless” and “ostracised”, and made to question their own “sanity”.

4. Discussion

All of the participants investigated in the current study presented PNES as having a debilitating effect on their lives. Individuals described struggling and at times appeared powerless

to deal with this impact. Difficulties were related to the consequences of PNES, the symptoms associated with seizures, and for some, pre-existing challenges such as dealing with a distressing life event or an illness. This is consistent with the notion that the treatment of PNES, in addition to aiming to achieve seizure control, should seek to explore and be responsive to a wide range of patients' needs [28].

Based on participants' writing rather than interview data, this study adds to the body of previous qualitative research investigating subjective experiences of PNES [5]. The themes that emerged from the current study are similar to those that were reported in a recent systematic synthesis of the literature, although our analysis provides further insights into at least two aspects apparently relevant to people with PNES.

Firstly, many individuals demonstrated feelings of low self-worth often engaging in acts of self-deprecation. Quantitative research has demonstrated that, when compared to those with epilepsy and healthy controls, individuals with PNES tend to report lower self-esteem [29]. Across a range of chronic illnesses low self-esteem has been associated with other problems including increased distress, anxiety, symptom severity, and reduced social interaction. More specifically, patients who view their symptoms as uncontrollable are at an increased risk of perceiving themselves as a *victim* of their condition which can deplete their self-esteem [30]. Compared to those with epilepsy, individuals with PNES report having less personal- and treatment-control over their condition [31], and a more external health locus of control [32]. This suggests that patients with PNES could benefit from interventions that aim to bolster self-concepts, such as self-esteem and self-worth. This supports the role of different therapeutic approaches in the management of PNES, such as Compassion-Focused Therapy [33] and Acceptance and Commitment Therapy [34].

Secondly, individuals described experiencing stigma related to their seizure disorder, as well as mental health-related stigma. Although PNES-related stigma has been reported in the literature [35,36], in-depth qualitative or quantitative investigations are notably lacking. The relative dearth of research is especially striking when the literature on PNES is compared to that on epilepsy. Individuals with epilepsy – as well as those experiencing difficulties with their mental health [37] – report that stigma can have profound and negative impact on different aspects of daily life [38,39]. Therefore, it is not surprising to find that participants in the current study were concerned about stigma. Stigma operates at different levels, namely self-stigma (individuals come to believe and apply the negative stereotypes associated with their situation to themselves) and public-stigma (others discriminate against individuals due to their situation). Certainly, in the current study participants' accounts support that this may be the case in PNES. Given the lack of research in this area and the substantial impact that stigma has on other patient groups, future investigations are needed into aspects of PNES-related stigma, such as its prevalence, consequence and management.

The research design and methodology utilised in the present study has also been used to examine the experiences of participants with epilepsy [18]. One of the most startling differences between the writings by patients with PNES and those of epilepsy was individuals' perception and experiences of HCPs. Participants with epilepsy described HCPs as a major source of support and knowledge. In sharp contrast, those with PNES described feeling “*let down*” and “*ostracised*” by HCPs. Unfortunately, such accounts are all-too-common in those with PNES. Rather than being treated and viewed as an individual with a very real, traumatic and disabling condition who (like any patient) is deserving of the best standard of care, many individuals with PNES report being regarded as having a factitious disorder, malingering

or being difficult to deal with [40]. There is no easy or quick fix to change the attitudes and behaviours of the HCPs who are responsible for delivering the unethical and unprofessional *care* many patients with PNES report having received. However, it is possible that better education of more HCPs about the causes, nature and manifestations of PNES may help. As a case in point, when investigating the illness perceptions of PNES in emergency care staff (n=30), 70% associated alcohol as a cause of PNES [41]. Better characterised treatment pathways for PNES could help HCPs feel less helpless when faced with individuals with PNES.

Although it is more common for quantitative research investigating PNES to compare different populations using the same methodology (e.g. PNES vs. epilepsy), there are several studies that have demonstrated comparisons can be made using qualitative datasets. These studies have revealed differences in how individuals' conceptualise, name, talk about, and describe their seizures, which mapped onto to the medical categories of epilepsy or PNES [42–49]. Further examination of the differences in individual's writings (and indeed other qualitative datasets) between PNES and other conditions (i.e. epilepsy, syncope, post-traumatic stress disorder) should be a line of future inquiry. What is more, differences between individuals with PNES could also be investigated, for example, those who score high vs. low on the psychopathology subscales, or individuals who report a past trauma vs. those who do not – although the group size of this initial exploration of written narratives of individuals with PNES did not allow us to do this meaningfully.

5. Limitations

This study was cross-sectional in design (data was collected over a maximum of two weeks); therefore, we are unable to draw any conclusions regarding the temporal characteristics of subjective symptoms associated with PNES. This has particular importance as individuals reported that certain characteristics of their seizures, such as the frequency or phenomenology, have changed over time.

We think that it is a strength of the current study that participants were recruited from a wider sample as opposed to a single centre. As such, we were able to recruit a greater number of individuals, and participants will have experienced a broader range of healthcare services. Although this approach should make our findings more readily generalisable, the benefits of our recruitment strategy must be weighed against the risk of including individuals in whom we were unable to confirm the diagnosis of PNES using their medical records. We note that the demographics of our participant group and the responses provided on self-report measures of depression and anxiety closely match those seen in larger quantitative studies of this patient group [1].

Although individuals were free to write about what they wanted to, the anchor questions were likely to have had an effect on their writing; for example, they may have encouraged people to engage in greater self-reflection. The fact that individuals in the current study engaged in acts of self-criticism, whereas such behaviours were not reported in another qualitative study interviewing patients with PNES about their emotions certainly hints at this [50].

This dataset was collected in the context of a randomised controlled trial that aimed to investigate the benefits of a therapeutic writing intervention. Therefore, it is likely that we will only have captured experiences from a subgroup of individuals, for instance, those who value psychological approaches, feel that they need additional support, and are able to (intellectually, physically and emotionally) write about their experiences of living with seizures. Findings from self-report measures suggest that there is at least a subgroup of individuals with PNES who exhibit

marked difficulties in the ability to express and describe feelings and bodily sensations [12,51].

6. Conclusions

This study set out to deepen our understanding of individual experiences of living with PNES by thematically analysing participants' written accounts of their condition. The results are in line with previous research suggesting that PNES can have a debilitating effect on many different aspects of daily life, some of which, individuals appeared helpless to deal with. As a result, treatments of PNES should seek to explore and address the wide range of patients' needs. Our findings highlight that more research is required into the stigma that individuals with PNES experience, and that efforts are needed to improve awareness of the condition amongst HCPs. Future qualitative research into the condition should aim to utilise different approaches to collect and analyse datasets – including comparing different clinical populations with PNES using the same methodological design – which is likely to produce the greatest insights into the condition.

Competing interests

None declared.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.seizure.2017.06.006>.

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