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Written accounts of living with epilepsy or psychogenic nonepileptic seizures: A
thematic comparison

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Abstract

This study examines the subjective experience of living with epilepsy or psychogenic nonepileptic seizures (PNES) by thematically comparing individuals' written accounts of their condition. Five key differences emerged. Theme 1: 'Seizure onset' revealed differences in how individuals think about and ruminate over the possible causes of their condition. Theme 2: 'Emotive tone' demonstrated that writings of those with epilepsy reflected stable emotions (no intense emotional reactions) whereas those of writers with PNES reflected anxiety and low mood. Theme 3: 'Seizure symptoms' showed differences in the conceptualization of seizures. Theme 4: 'Treatment' explored differences in the diagnostic journey and experiences of healthcare professionals. Theme 5: 'Daily life' revealed that those with epilepsy perceived sequelae and seizures as something that must be fought, whereas those with PNES tended to describe their seizures as a place they enter and something that has destroyed their lives. The findings have implications for treatment and management.

Introduction

The manifestations of psychogenic nonepileptic seizures (PNES) superficially resemble those of epileptic seizures. However, whereas epileptic seizures are caused by excessive electrical discharges in the brain, PNES are understood as a dissociative response to potentially distressing stimuli (Brown & Reuber, 2016; Brown & Reuber, 2016). As such, PNES are classified as a mental disorder in the current medical nosologies (APA, 2013; WHO, 1992). PNES are not rare, as approximately 20% of patients referred to epilepsy clinics will have the condition (Angus-Leppan, 2008).

Findings from qualitative and quantitative research illustrate the negative impact that epilepsy or PNES can have on different domains of daily living. While people with epilepsy typically report a lower health-related quality of life (HRQoL) and more symptoms of psychopathology than healthy controls (Taylor, Sander, Taylor, & Baker, 2011), those with PNES report greater problems than both these groups (Brown & Reuber, 2016; Jones, Reuber, & Norman, 2016). Not only do individuals living with epilepsy or PNES have to adjust to the unpredictability and distressing nature of seizure events, they also have to manage the sequelae associated with their seizures. For many, stigma, discrimination, the limitation of activities, and the challenges associated with treatment is a greater burden than seizure events themselves (Kerr, Nixon, & Angalakuditi, 2011; Rawlings & Reuber, 2016; Walker et al., 2014).

Qualitative research has a particularly important role to play if we want to understand how epilepsy or PNES affect individuals. Over the last decade there has been an increase in the number of publications using qualitative methodologies to investigate individuals' perception of living with epilepsy or PNES. For example, using different forms of language analyzes to examine English, German and Italian speaking patients, a series of studies compared how individuals with epilepsy or

PNES talk about their problems when they present to a healthcare professional. These studies revealed differences in how individuals' conceptualize, name, talk about, and describe their seizures, which were clear enough to contribute to the clinical differentiation of epilepsy and PNES (Cornaggia et al., 2012; Monzoni, Grünewald, Reuber, & Duncan, 2011; Plug, Sharrack, & Reuber, 2009, 2010; Plug, Sharrack, & Reuber, 2011; Robson, Drew, Walker, & Reuber, 2012; Schwabe, Howell, & Reuber, 2007; Schwabe, Reuber, Schondienst, & Gulich, 2008).

To date, qualitative research examining PNES and epilepsy has predominantly relied on research interviews or the audio- and video-recording of actual clinic conversations for data collection (Rawlings & Reuber, 2016). Using various methodological and analytical approaches are likely to produce different perspectives on a particular problem (Farmer, Robinson, Elliott, & Eyles, 2006). Recently, the subjective experience of living with epilepsy (Rawlings, Brown, Stone, & Reuber, 2017a) or PNES (Rawlings, Brown, Stone, & Reuber, 2017b) has been thematically analysed by examining individuals' written accounts of their condition. Compared to spoken responses for example, writing is seen as an individual act allowing for private reflection, exploration and expression of thoughts and feelings (Howlett, 2004). These analyzes have helped further to illuminate how individuals are affected by and subsequently manage their condition, and highlighted implications for clinical practice. An important finding of this research was that, there were clear differences in the emergent themes between individuals with epilepsy and those with PNES. In order to explore how two disorders characterized by similar key symptoms (seizures) but attributable to different causes (predominantly neurological or psychogenic) are represented by individuals affected, the present analysis was intended to focus specifically on similarities and differences in the narratives of patients with epilepsy and those with PNES. Ultimately aiming to improve communication between patients

and clinicians, we wanted to explore which experiences are common to both or specific to one of these disorders.

Methods

The dataset used for this study 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 allocated to the *intervention* group – the control condition involved writing about daily events devoid of emotion.

Participants

Participants were approached consecutively and recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield (United Kingdom). Individuals were also recruited through membership-led organizations for individuals experiencing seizures (see acknowledgements for the list of organizations). 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 in the present study if they were over the age of 18 years; had a diagnosis of epilepsy or PNES (individuals with dual-diagnosis were excluded); were able to provide informed consent; complete a demographic and clinical questionnaire without help; and read and write in English. The diagnoses of all participants recruited at the Royal Hallamshire Hospital were confirmed by review of their hospital records. When possible, confirmation of the self-reported diagnoses of participants recruited through membership-led organizations was sought from their general practitioner.

Clinical profile of participants

Participants completed a demographic questionnaire that recorded their age, gender, employment status, years of education and diagnosis (epilepsy or PNES). Participants were also asked how long they had experienced seizures and the date of their last seizure. To investigate the effectiveness of the writing intervention, participants completed a number of widely used validated self-report questionnaires at baseline and during follow-up. Here we only report some of the baseline data in order to describe our participant group and allow comparisons of clinical profiles in our groups with individuals with epilepsy or PNES reported elsewhere. In order to determine whether any group level differences between participants with epilepsy and PNES are likely to be explained by chance alone, the statistical significance of differences was tested using chi-square or Mann-Whitney U tests as appropriate. P values of <0.05 were considered significant.

Participants' HRQoL was investigated using the NEWQOL-6D (Mulhern et al., 2012). This is a six-item HRQoL measure specifically developed for individuals with seizures. A higher score represents a better HRQoL (highest possible score 0.96 – 0.34 lowest possible score). The Generalised Anxiety Disorder (GAD-7) was used to measure anxiety (Spitzer, Kroenke, Williams, & Löwe, 2006). 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 (Gilliam et al., 2006). A score >15 suggest a current major depressive episode. Seizure frequency and severity were investigated using the Liverpool Seizure Severity Scale questionnaire (LSSS-3) (Baker, Smith, Jacoby, Hayes, & Chadwick, 1998). This is scored from 0–100 with a higher score representing greater seizure severity.

Data collection

A total of 19 participants with PNES and 20 with epilepsy were included in the study. This is the number of individuals that had been recruited to the writing intervention when the current study was undertaken.

Participants recruited from outpatient neurology clinics were sent a participant information sheet at least 48 hours before their appointment with a Consultant Neurologist. On the day of their appointment, individuals were approached by a member of the research team and invited to take part in the study. Those who gave written consent were asked to complete a set of self-report measures (see above). Participants recruited from membership-led organizations replied to an advert for a study of a writing intervention for individuals with seizure disorders. Potential participants then contacted a member of the research team who gained written informed consent and provided access to an online form allowing participants to complete the self-report measures.

Participants were then given four writing booklets to complete. Each booklet contained writing instructions, space for writing (four A4 sheets of lined paper) and a link to a website where they could submit their written account if they preferred typing to handwriting. Participants were asked to produce four pieces of writing: 1) their very deepest thoughts and feelings about their condition (Pennebaker & Chung, 2010); 2) a letter to their condition (Howlett, 2004); 3) a letter to their younger self (Kress, Hoffman, & Thomas, 2008); and 4) about a personal value (McQueen & Klein, 2006). These topics had been set based on previous studies of writing therapies in other patient groups. Participants were asked to write for at least 20 minutes per question at home, in private and unsupervised.

Data analysis

Broadly replicating the approach of a thematic comparison in a different patient group (Tang et al., (2009), the data were analyzed in three main stages:

In the first stage, a member of the research team transcribed and read all writings to become familiar with the content. This research member was undertaking a PhD in Clinical Neuroscience and has previously published qualitative research. Participants' answers to each of the four questions were read separately, but as individuals discussed similar events throughout and expanded on experiences in later sessions, it was decided that their writing on all four topics would be considered together for the analysis. This research member aimed to work reflectively throughout, keeping a journal of his impressions and reflections specific to the diagnosis, as well as differences between the diagnoses.

In stage two, separate thematic analyzes were conducted on participants' writings about epilepsy or PNES (Table 1). The analyzes were guided by the framework outlined by Braun and Clarke (2006). A mixed inductive and theoretical approach was used. The groups were read and coded independently of each other.

In the third stage, the themes that emerged from analyzing the writings from participants with epilepsy and PNES were examined and summarized using a data-driven approach. Key differences were defined, based on the relevance, prevalence and perceived importance of the data.

Individuals were informed that a member of the research team would read their writing to gain a better understanding of what it is like to live with their condition, but that they would not be contacted about what they had written. While this meant that participants might have felt that they were able to be more honest and open in their writings, we were unable to achieve member checking. However, expert

checking was performed as all the emergent themes were shared between the authors and revisions were made until a general consensus was achieved.

Throughout this report, in the quotes used (“ ”) [Start] and [End] have been added to represent the beginning and conclusion of citations from narratives. The main themes are presented in the order in which the differences between the two conditions were observed, for example, theme one and two reflect differences in how individuals began their narratives.

Table 1 Stages of thematic analysis.

Stage	Action(s)
1	A member of the research team 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.
2	A member of the research team compared and collated codes to create main and sub-themes.
3	Reviewed the themes and codes to define sub-themes. It was at this stage that the themes were shared between the authors allowing for changes. Theoretical saturation was not possible as participants were not directed in their narratives and so they could choose to write about anything.
4	Further refinement of sub-themes, assigning clear titles and definitions.
5	Writing the report, making the explanation of themes and sub-themes coherent.

Results

The PNES and epilepsy patient groups were similar to those reported in most previous studies of these populations (Brown & Reuber, 2016): participants with epilepsy had experienced their seizures for longer and reported fewer seizures. Participants with PNES reported more prominent symptoms of anxiety and depression on self-report questionnaire. In both groups, the overwhelming majority of participants were female. The epilepsy and PNES groups did not differ in terms of age, gender, years of education, HRQoL, seizure severity, number of written words produced and method of recruitment (Table 2).

The thematic analysis in the epilepsy group yielded five key-themes and in the PNES group, six key-themes (Figure 1). The thematic comparison revealed five key

differences in terms of (i) seizure onset, (ii) emotive tone, (iii) seizure symptoms, (iv) treatment, and (v) daily-life. These differences have been summarised in Table 3.

Table 2 Clinical profiles of participants in the epilepsy and PNES groups. Scores reflect median (Interquartile range) unless stated.

	Epilepsy	PNES	<i>p</i> value
N	20	19	0.87
Age	52.5 (23.5)	42 (24)	0.07
Gender (% of female)	85%	84.2%	0.64
Years of education	14 (6.3)	16 (5.5)	0.55
HRQoL	0.77 (0.12)	0.67 (0.18)	0.07
Seizure severity	51.3 (33.1)	52.5 (21.8)	0.55
Years since seizure onset	25.5 (30.8)	5 (5)	<0.001
Seizure frequency (last 4 weeks)	1 (4.8)	20 (46)	<0.001
Words produced	1,762 (2,318)	1,898 (1,964)	0.55
GAD-7	3.5 (5.8)	9 (16)	0.007
None (0-4)	60%	26.3%	
Mild (5-9)	20%	31.6%	
Moderate (10-14)	10%	0%	
Severe (>15)	10%	42.1%	
NDDI-E	12 (7.8)	17.5 (7.5)	0.001
Recruited from neurology clinics (%)	40%	21%	0.2
Score >15	25%	66.7%	

PNES = Psychogenic Nonepileptic Seizures, HRQoL = Health Related Quality of Life, GAD-7 = Generalise Anxiety Disorder, NDDI-E = Neurological Disorder Depression for Epilepsy.

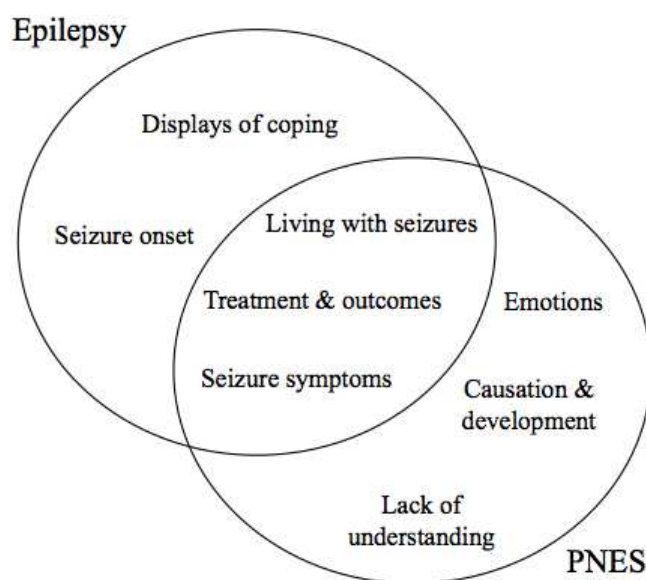


Figure 1 Comparative diagram highlighting overlapping and non-overlapping key themes from the thematic analyzes investigating written accounts from individuals with epilepsy or psychogenic nonepileptic seizures (PNES).

Table 3. A summary of thematic differences between individuals with epilepsy and psychogenic non-epileptic seizures (PNES)

	Epilepsy	PNES
1. Seizure onset	Seizures were described as coming on out of the blue. Participants rarely reported other conditions. Participants did not ruminate over the cause of their condition.	Reports of past trauma were common. Precipitating factors were evident, as participants would discuss past experiences of stress, chaos, and turbulence. Participants often reported other medical diagnoses, which were perceived as being connected to PNES.
2. Emotive tone	Relatively stable. Mood changes (frustration, anger, depression) were discussed as being associated with their seizures or medication.	Narratives reflected low mood and anxiety - often this was chronic. Notable lack of self-worth and self-appreciation. Discussed problems with emotional processing.
3. Seizure symptoms		
3.1 Seizure descriptions	Seizures were described as external and conceptualized as acting independently of the writer. Seizures would follow participants around, “stalk” and “come on” or “hit” them. Participants projected human characteristics onto their seizures.	Seizures were conceptualized as a state or place that participants enter. Seizures were not discussed as following participants around. Seizure experiences varied greatly.
3.2 Focus on seizure symptoms	Participants’ narratives focused on living with epilepsy, and how it has interfered with their daily lives. Seizures were described as secondary to other factors.	Participants would focus on their post- and interictal symptoms. Problems associated with seizure events, as well as living with PNES.
3.3 Postictal experiences	Described in detail, some individuals explained that they could get back on with their day as normal. Seizure-related injuries were commonly discussed.	Described in detail, severe and disabling symptoms. Seizure-related injuries were rarely reported.
3.4 Seizure-related fear	Mainly anticipatory fear.	Anticipatory and ictal fear. It was clear that seizures were a difficult experience.
4. Treatment		
4.1 Diagnosis	An important moment, but a relatively brief event that participants did not expand upon. For some, it changed their identity.	Participants resisted the diagnosis, looked for other diagnoses, asked for other tests. Long process.
4.2 HCPs	A major source of support and seizure management. Trusting the medical doctors.	Participants felt let down, ostracized, unsupported, belittled, disbelieved, and did not trust HCPs. Passed onto different services, little validation even after diagnosis. Negative and at times damaging experiences.
4.3 Perceptions of treatment	Viewed as the main method of seizure control- albeit side effects were a major source of distress.	Cries for help, not sure of the best approach, skeptical of therapy.
5. Daily-life		
5.1 Presentation of sequelae	Portrayed themselves as coping well and having integrated epilepsy into their lives. Strived to live a normal life. Accepted or resisted limitations posed by epilepsy. Downplayed their symptoms. Found positive gains. Used laughter. Promoted self-autonomy in daily life. Participants described themselves as fighting the condition and winning.	Participants seemed to be struggling to live their lives due to their seizures. Emotional expression of helplessness in opening and ending statements. Maladaptive coping tendencies such as self-harming, dissociation, or not processing their emotions.
5.2 Comprehension of disorder	Participants seemed to be knowledgeable about their condition and did not explicitly express a wish to know more.	Participants lacked the understanding of their condition e.g. why it started, what the triggers were, how to stop them. Participants asked many questions. Participants described feeling “lost”

PNES = Psychogenic Nonepileptic Seizures, HCP = Healthcare professional

Theme 1: Seizure onset

Participants with epilepsy choose to describe the events surrounding the onset of their condition at the very beginning of the first writing session, and then would rarely, if ever, write again about the experience or ruminate about the cause. Developing seizures was typically described as an event that had changed their lives or themselves “*forever*”. Individuals explained feeling shocked, frightened, and struggled with altered self-identities as a result.

Epilepsy: [Start] “I often wonder what my life would have been like without my epilepsy. It was such a shock to me and my family when at the age of 11 I started having seizures...that’s when I became different from my twin sister” (Female, 58 years old, last seizure was in 2012)

Participants with PNES appeared to explore the possible causes of their condition throughout their narratives. Although they had been asked to write about their experiences of living with their condition, 16/19 participants spontaneously reported a past trauma, such as abuse (e.g. physical, sexual, emotional) or a distressing event (e.g. bereavement). Participants commonly perceived comorbid conditions (emotional or organic) as linked to PNES. For some, it was almost as if their seizures were yet another set of symptoms or problem that they had to manage and overcome. This also gave the impression that participants perceived their seizures as a consequence of other events in their lives, for example, their relationship with another person. In contrast, those with epilepsy depicted the development of seizures as sudden and unprovoked (“*out of the blue*”).

PNES: [Start] *“I HATE this condition. My life was great before I got “ill”, well most people would call my life hard but it was great to me. I was finally in a stable place, after a string of life events; one alone would test the strongest of people, but I felt “nothing could stop me now”. I’d left an abusive relationship I’d had for eight years.”*
(Female, 31 years old, 30+ seizures in the last 4 weeks)

Theme 2: Emotive tone

One of the most prominent differences between the two groups of individuals was the emotional tone of their writing. Participants with epilepsy seemed emotionally stable and fluctuations in mood were often described as associated with postictal symptoms or adverse effects of anti-epileptic medication.

In contrast, the writings of individuals with PNES were very negative, reflecting low mood, and increased levels of anxiety. These emotions appeared to stem from the development of PNES, but in some cases, they were also discussed as a long-term characteristic. A key example of the difference in emotional tone was how participants began and ended their writing sessions. Participants with epilepsy would often begin their narratives in chronological order, describing events surrounding the onset of their condition and what had happened during their first seizure - their narratives might have also end with a statement of defiance. By contrast, those with PNES tended to begin with an expression of suffering and finish on a negative note.

Epilepsy: *“There have been times of course when my positivity has left me in hospital or when I lost a lot of weight due to problems caused by medication, but I usually get my fight back later on.”* [End] (Female, 57 years old, 1 seizure in the last 4 weeks)

PNES: *“I just wish there was a way to have it all go away and not have to worry about my condition anymore and get back to normal. I just need some help.”* [End]
(Male, 42 years old, 20 seizures in the last 4 weeks)

It seemed that participants with PNES were struggling with their condition, and at times, expressed a sense of powerless. Moreover, participants described hating themselves, writing that they are “*worthless*”, “*weak*” or “*useless*”. Such expressions of self-depreciation were almost non-existent in those with epilepsy.

Individuals with PNES were more likely to describe that they suppress their emotions or not “*letting anyone in*”. Some described that this has contributed to the development of their condition. Moreover, following the manifestation of their seizures, those with PNES often described how they might struggle to regulate or control their emotions.

Theme 3: Seizure symptoms

Seizure descriptions

Differences in how individuals wrote about their seizures were observed. Those with epilepsy would tend to describe their seizures as an external, independently (sometimes hostile) acting agent. Seizures were reported as following them around or “*stalking*” them. Similarly, several participants projected human characteristics onto their seizures, such as giving them a name or consciousness.

In comparison, participants with PNES were more inclined to describe their seizures as a place or a state that they enter, and in which, the individual retains agency in the seizure.

Epilepsy: *“I call my epilepsy Bob... It’s much easier to say “Bob’s been a bit of a nuisance today’ or ‘Bob just paid me a visit!’”* (Female, 71 years old, 4 seizures in the last 4 weeks)

PNES: *“I often think I am back in that hell hole, having just relived the whole thing again whilst in (sic) seizure.”* (Female, 43 years old, 120 seizures in the last 4 weeks)

Focus on seizure symptoms

Participants with PNES appeared to focus more on their post- and interictal symptoms. When individuals did describe seizure episodes, it would often be of the situation or circumstances of particular seizures.

Those with epilepsy, however, centered their narratives on how the condition has affected their daily life, for instance, the challenges it has posed to gaining employment. Seizure episodes did not dominate individuals’ experience of living with epilepsy. This gave the impression that “*secondary*” issues such as the side effects of medication, the restrictions imposed because of epilepsy, and the anxiety about having another seizure were the biggest challenges. In contrast, for those with PNES, it was also the actual episodes themselves that were problematic.

Epilepsy: *“Currently epilepsy effects my life more due to secondary symptoms, mostly those I have from the anti-epileptic drugs.”* (Female, 40 years old, 0 seizures in the last four weeks)

PNES: *“I suppose - by now - it is safe to say it [PNES] has ruined me, basically. Having a seizure every one till two/two and a half hours does not leave much room for anything else.”* (Female, 31 years old, 340 seizures in the last 4 weeks)

Post-ictal experiences

Both groups tended to report their postictal symptoms in detail; however, those with epilepsy were more likely to describe themselves as getting back on with their day as normal, or that they would not let it affect them. Seizure-related injuries were described more commonly by those with epilepsy, than those with PNES.

Epilepsy: *“I had three seizures before I went to work this morning but so...? I still went to work, did a full day and had lunch in the pub.”* (Female, 36 years old, 5 seizures in the last 4 weeks)

PNES: *“When I have a seizure I black out and have no idea what is going on and wake up sometimes groggy and really weak and not knowing who or where I am.”* (Male, 42 years old, 20 seizures in the last 4 weeks)

Seizure-related fear

While both groups described that they were afraid of triggering or having a seizure, individuals with PNES were more likely to state that the seizure itself involved fear or that it was a horrible experience.

Epilepsy: *“Epilepsy is something I have learned to live with, some days (particularly when a severe fit rears it ugly head) I feel scared out of control and useless.”* (Female, 62 years old, 2 seizures in the last 4 weeks)

PNES: *“The way these seizures make me feel is this. Until recently, genuinely I believed that I was indeed dying.”* (Female, 46 years old, 224 seizures in the last 4 weeks)

Theme 4: Treatment

Diagnosis

Unsurprisingly, the diagnostic journey was a key part in the narratives of participants with PNES. Some individuals appeared to reject or resist the diagnosis, whilst no participant with epilepsy reported such a reaction – in fact, some individuals with epilepsy explained that their diagnosis came as a “*relief*” as it validated what they were experiencing.

Epilepsy: *“[letter to younger-self]...it turns out you have epilepsy. It’ll be scary thinking about it at first but honestly; it’s such a relief. I remember the unknown and it sucks, so don’t worry your answer is coming!”* (Female, 27 years old, 0 seizures in the last 4 weeks but typically averages 1 seizure every other month)

PNES: *“I accept that they may be psychogenic ... but I’m not yet convinced that there is no physical link.”* (Male, 69 years old, 7 seizures in the last four weeks)

Experiences of healthcare professionals (HCPs)

With very few exceptions, participants with epilepsy uniformly described HCPs in a positive manner, perceiving them as helpful, supportive and a valuable source of knowledge. This was in total contrast to the experiences described by those with PNES. Individuals reported past experiences in which HCPs failed to listen and did not believe that their symptoms were real, and beyond their control. Participants

described having avoided healthcare services in the past because of previous adverse experiences. Individuals explained feeling let down and ostracized by HCPs.

Epilepsy: *“My wonderful, calm, patient neurologist has listened to, heard and prescribed”* (Female, 59 years old, last seizure was in 2014)

PNES: *“What a life, but at least most days now I don’t end up at that shitty hospital where the doctors treat you like shit and call you a fake. How I have never been arrested there I don’t know.”* (Female, 43 years old, 120 seizures in the last 4 weeks)

Perceptions of treatment

Given the differences in the acceptance of their diagnosis, it follows that participants perceived their treatment differently. Those with epilepsy viewed their medication as key to seizure control, and viewed the side effects as a compromise. In PNES however, individuals described difficulties finding and securing access to psychological or specialized care. Participants seemed skeptical of therapy and perceived it as an approach to treat their seizures opposed to changing other aspects of their life.

Epilepsy: *“I have a high dose of the medication that I take and need that high dose to control the seizures as well as is feasibly possible in my body.”* (Female, 40 years old, 0 seizures in the last 4 weeks)

PNES: *“I came across a psychologist though, yesterday to be fair and she was amazing. Although she did not have much knowledge of functional neurological disorders apart from what she had to Google, she sat back and listened... So my*

hopes are raised a little more with the extra help that I may receive (but I wont hold my breath). ” (Female, 26 years old, 2 seizures in the last 4 weeks)

Theme 5: Daily life

Presentation of sequelae

The two groups differed greatly in their descriptions of how they depicted themselves as living with their condition. Participants with epilepsy appeared keen to present themselves as having integrated the condition into their lives and would report that they are “*coping*” with the adversity. For the most part, individuals appeared to be fighting, striving to live a *normal* life, and persevering “*despite*” having epilepsy. In comparison, nearly half of those with PNES explicitly stated that their condition had “*destroyed*” their life or produced cries for help.

Epilepsy: *“Everyone is running, cycling, on the stepper and there is little old me just walking on the treadmill... At first it bothered me that I couldn’t run like the others but then I just accept that’s how it is and aim for my 3 miles, at least I have my music on and reach my goals, the same as everyone else!” (Female, 34 years old, 0 seizures in the last 4 weeks but typically experiences 2 seizures a year)*

PNES: *“This condition seems to have taken my life away from me.” (Male, 42 years old, 20 seizures in the last 4 weeks)*

Those with epilepsy would downplay and minimize the severity of their condition. Participants would also describe the benefits of laughter and report having gained positive insights from developing the condition. This was rarely observed in PNES.

Epilepsy: [Letter to seizures] *“There have been times I’ve screamed at you in frustration ...but there’s also things that without you I would probably not have learned. If I am only to have only half a life then I will make it count.”* (Female, 56 years old, 7 seizures in the last 4 weeks)

Individuals with PNES would describe and show insight into their coping behaviours that may not be useful, for instance, self-harming, bottling it up and dissociating. Those with epilepsy would tend not to describe specific coping strategies but when they did, it was often practical behaviours such as, keeping a diary to aid with memory and relying on friends and family.

PNES: [Letter to younger self] *“When bad things happen to you, do not bottle it all in. This will not help you in the long run. You are better off telling someone, anyone as hard as that may seem it is better option I promise you, it’ll be easier that way.”* (Female, 26 years old, 35 seizures in the last 4 weeks)

Comprehension of disorder

Those with epilepsy seemed to present themselves as knowledgeable about their condition, for example, they would give advice to their younger selves about how to cope. In contrast, participants with PNES described themselves as “lost”, stating explicitly that they wanted to know more about PNES, for instance, why they had developed seizures, what caused them, and how to stop them.

PNES: *“Until there is more understanding on the condition and how to explain things to anyone diagnosed then it’s a lost world I seem to have been put into and one I’d like to find my way out of.”* (Female, 31 years old, 30+ seizures in the last 4 weeks)

Differences in outcome expectations were also observed. Participants with epilepsy appeared better able to accept that they had developed seizures, and some seemed content that they would have their seizure disorder for the rest of their lives, while others were determined to be free of it.

Epilepsy: *“It defines me it’s part of who I am, my identity. I don’t like that I’ve allowed that to happen”.* (Female, 27 years old, 0 seizures in the last 4 weeks)

In contrast, participants with PNES seemed to be confused about the nature of their seizures and unsure of the disease timeline. Although some individuals did express the desire to be seizure free or have their old life back, this appeared to be a “*wish*” rather than an expectation. Participants with PNES came across as wanting to manage or “*beat*” their disorder, however, they did not know how to and experienced almost every day as a struggle.

PNES: *“I am now 26 and living with the man I want to spend the rest of my life with...I just hope that my seizures and illness wont get in the way of our life and hopefully our plans to start a family.”* (Female, 26 years old, 35 seizures in the last 4 weeks)

Discussion

In this study we utilized a thematic comparison to examine written accounts of living with epilepsy or PNES. While there were overlaps between the topics that participants chose to write about (Figure 1), we found more differences than similarities between the two patient groups. From the analysis, five key themes emerged reflecting differences in terms of 1) how individuals think about and

ruminate over the possible causes of their condition; 2) the emotive tone of writings; 3) the symptoms and conceptualization of seizure events; 4) experiences of treatment, management and care; and 5) effects of seizures on daily life. While the accounts are in line with the notion that both epilepsy and PNES are biopsychosocial disorders associated with significant effects on social, psychological and emotional functioning (Elliott & Richardson, 2014; Reuber, 2009), there was great variation in how the two groups presented themselves as living with and managing their condition.

Within Western societies there is a growing pressure to be *successfully ill*. For example, those with long-term disorders are expected to accept that their condition maybe chronic, but rise to the challenge, champion their story, find meaning and achieve personal growth (Frank, 1997; Lee & Poole, 2005). This, for the most part, was reflected in the narratives of participants with epilepsy. These individuals were keen to present themselves as coping, and would often state that they would not let it “win”. Participants expressed that they are living a “normal” life, although they admitted that this is occasionally interrupted, albeit briefly, by events associated with their condition. Similar findings have been reported elsewhere. Admi and Shahm (2007) interviewed 14 young people with epilepsy who reported that, although their condition had a clear impact, they would not let it play a central role. Instead, they stressed that they are “normal” people who are coping with and trying to prevent epilepsy from interfering with their lives. A study using Conversation Analysis demonstrated that patients with epilepsy tend to be keen to present themselves as coping well with their condition when they talk to doctors in clinical encounters (Monzoni & Reuber, 2009). This was rarely observed among those with PNES. Instead, participants wrote about how PNES has “destroyed” their lives, the negative reaction of others (often that of HCPs) and focused on the disabling nature of their

seizures. Individuals appeared powerless and described feeling left to manage their condition without any or with very little support.

The tendency for those with epilepsy to normalise experiences associated with their condition has previously been contrasted with that of individuals with PNES, who were found to have a propensity to catastrophize about such events. Using content analysis, Robson et al. (2012) investigated the use of “third party references” (i.e. instances where individuals with seizures refer to others not present during their one-to-one interaction with a doctor) by patients with epilepsy or PNES. The results demonstrated that the two patient groups made a similar number of such references, however, 12 out of 13 patients with PNES used third party references to catastrophize about their seizure events whereas, only one patient out of seven with epilepsy did. Six patients with epilepsy made normalizing references while only two did with PNES. The reason for this difference between the two conditions is unclear. Based on our findings (and those reported elsewhere), we can posit a number of suggestions:

First, it seemed that, experientially, non-epileptic seizures were a more negative and difficult experience compared to epileptic seizures. This could make them harder to normalize or downplay. Supporting this notion, individuals with PNES have been found to report an association of their seizures with fear or panic more frequently than those with epilepsy (Rawlings et al., 2017)

Second, and related to the first, in the current study and the one by Robson et al. (2012), the frequency of seizures was greater in those with PNES compared to individuals with epilepsy. This means that seizure events may have dominated and constituted a larger part of their daily life. Having or recovering from seizures may take up a large part of their day – in the current study it appeared that experiencing and recovering from nonepileptic seizures poses greater challenges to individuals than having or recovering from epileptic seizures. That said, research has demonstrated

there is little evidence to suggest a strong association between PNES frequency or severity and HRQoL (Jones et al., 2016).

Third, it seemed that those with epilepsy possessed a greater sense of self-efficacy towards coping with their condition compared to individuals with PNES. Self-efficacy is an individuals' perceived ability to manage difficult situations. While this belief has not yet been investigated in PNES, an association between self-efficacy, and self-esteem and life satisfaction has been reported in epilepsy (Sung, Muller, Ditchman, Phillips, & Chan, 2013). Further research is needed into the concept of condition-related self-efficacy in PNES, as it could be a potential mechanism of change.

Fourth, individuals with PNES may exhibit a greater tendency to engage in cognitive distortions, for example, holding onto negative thinking patterns. Although caution should be used when attempting to draw formulations simply from patient's written accounts, other forms of negative thinking (in addition to catastrophizing) were evident in the writings of those with PNES. For instance, study participants with PNES often used negative self-labeling, whereas this was not observed in the written accounts of those with epilepsy. This supports the use of different psychological therapies for those with PNES. For example, cognitive behavioural therapy (Goldstein et al., 2010), mindfulness (Baslet, Dworetzky, Perez, Dworetzky, & Oser, 2015), and acceptance-commitment therapy (Cope, Poole, & Agrawal, 2017). Individuals with epilepsy may also benefit from such treatments to help manage with the sequelae of their condition (Dewhurst, Novakova, & Reuber, 2015; Thompson et al., 2015).

Finally, the manner in which others perceive their condition may also influence how individuals identify and present with their symptoms. For example, in PNES, two qualitative studies reported that patients expressed a sense of doubt about the diagnosis, which in part, seemed to be related to the HCPs perceptions of their

disorder (Thompson, Isaac, Rowse, Tooth, & Reuber, 2009; Wyatt, Laraway, & Weatherhead, 2014). The term *sick role* has been used to describe the behaviour that people adopt in order to manage their condition. The *unconditionally legitimate sick role* refers to those with a chronic condition that is perceived as beyond their control. These individuals are automatically entitled to enter the sick role. Epilepsy is a condition that has a clear pathophysiological cause, and so compared to PNES, which are psychogenic, individuals may find it easier to occupy the sick role or have it applied to them by others. For instance, participants reported struggling with altered or new self-identities as a result of developing their condition. However, given the finding that individuals often stressed being “normal”, this would suggest some do not identify with this role. The *illegitimate role* is reserved for those with a condition that is associated with misconceptions or where there is a sense that individuals are responsible for their symptoms and do not have the right to assume the sick role (Giddens, 2013). Participants with PNES described how they have been accused of faking their seizures, felt ostracized, or that very few people (including themselves) understand their condition. As such, they may feel the need or perceived necessity to show that they are *legitimately* sick. Catastrophizing their experience may serve this purpose by highlighting the severity of the condition and by communicating that their problems could not possibly be made up. Individuals were observed ruminating over the aetiology of their condition searching for other causes that are non-psychological. Indeed, the desire for *legitimacy* may contribute to patients with PNES resisting or dismissing their diagnosis (i.e. a psychosocial interpretation of their symptoms) (Monzoni, Duncan, Gruenewald, & Reuber, 2011a, 2011b).

There were notable differences in how individuals conceptualized their seizures. In epilepsy, seizures were described as an independent agent that individuals may fight off, impacting them from the outside. This again, is consistent with societal

norms as metaphors of battle are often used and encouraged where illness is perceived as a threatening entity that must be battled with (Kielhofner, 2008; Markle, Attell, & Treiber, 2015). In comparison, in PNES, seizures seemed to be a state or place that participants find themselves in. This difference is consistent with a series of studies using linguistic analyzes to investigate how people talk about their seizures in clinical interviews with HCPs (Cornaggia et al., 2012; Plug et al., 2009; Schwabe et al., 2008). Further research is required to examine if seizure conceptualization is linked with outcome and perception of illness, or if these linguistic differences are merely a consequence of different ictal experiences.

Differences between the two conditions in the reported experiences with and perceptions of HCPs were striking. In writings by those with PNES, stories describing how individuals felt discriminated against due to their diagnosis or let down by HCPs constituted a major part of the narratives. The difference in the perceptions of healthcare providers of those with epilepsy and PNES observed here mirrors findings of previous studies. For example, Karterud et al. (2010) analysed transcripts of interviews with ten individuals whose diagnosis had changed from epilepsy to PNES and reported that individuals described a 'transfer of responsibility' from HCPs to themselves. One patient explained feeling left to deal with the condition on her own, whereas with epilepsy, she would be offered support from a multi-professional team at an epilepsy centre. It is clear that, in addition to improving the understanding and sensitivity towards PNES, greater efforts are needed to help HCPs feel more confident to provide care for patients with this condition and to insure everyone involved in their treatment is working to a consistent model (Worsely, Whitehead, Kandler, & Reuber, 2011).

Limitations

We chose to recruit individuals from both neurology clinics and membership-led organisation. Whilst this means that we were able to gather a more diverse range of experiences than if participants had been recruited from a single centre, we were unable to confirm all diagnoses or the demographic information provided because we did not have access to all participants' medical records. Theoretical saturation was not achieved. The primary reason for this is that, the four anchor questions were open and non-directive, for example, individuals were given prompts and instructed that they "could" or "may" want to write about certain topics, and as such, the possible responses (and emergent codes) were endless. This may impact the reliability of our findings as we failed to reach a stage in the analysis where collecting additional data would not lead to additional themes emerging. As such, throughout the results, we have reported the number of individuals who described a certain experience. This provides context to the emergent difference, for instance, demonstrating how common or uncommonly a particular theme featured in different narratives. However, the reader should realise that these numbers have to be interpreted with caution. The fact that 16/19 contributors may have mentioned a particular theme does not automatically make this theme more prominent or important than one that was highlighted as most important by 8/19 for example. As in most previous studies (Brown & Reuber 2016a), individuals with epilepsy or PNES differed in terms of some clinical features – such as the number of reported symptoms of psychopathology (anxiety and depression), and the duration of their seizure disorders. This is likely to have had an effect on individual's narratives; for example, any dissimilarities observed between the written accounts may not be due to differences in the experience of living with PNES or epilepsy, but to a third factor, for instance the levels of anxiety or depression.

Conclusion

In this study we demonstrate that clear and important differences can be observed between lived experiences of epilepsy and PNES based on written accounts of the condition. Those with epilepsy appeared to conform to Western societal norms of illness as seizures and the sequelae of epilepsy were both conceptualized as something that must be fought. In contrast, those with PNES rarely used fighting terminology and instead were likely to describe their seizures as a place they are in or state they enter. Our findings suggest that helping individuals to develop a sense of self-efficacy, to understand the nature of their condition, and to develop specific coping mechanisms targeting cognitive processes could be beneficial in both conditions. Future research should look to use different methodological and analytical approaches to further examine subjective phenomena associated with epilepsy and PNES.

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Competing interests

None declared.

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