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Review

What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies[☆]

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A R T I C L E I N F O

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A B S T R A C T

Purpose: This is a narrative systematic synthesis of qualitative research investigating patients' accounts of living with psychogenic nonepileptic seizures (PNES). Qualitative methodologies allow patients to share lived experiences in their own words. The examination of patients' own accounts is likely to offer revealing insights into a poorly understood, heterogeneous disorder.

Methods: We identified 21 separate studies about PNES published after 1996 and based on analyses of patients' own words. Papers were synthesised inductively and deductively using an iterative approach.

Results: Five key themes emerged from the synthesis of studies capturing accounts from over 220 patients, reflecting experiences of seizure events, diagnosis, treatment and management, emotional events, and impact on daily life. Patients with PNES discussed the phenomenology of their seizures differently from those with epilepsy. PNES were experientially heterogeneous. Many patients shared a sense of uncertainty surrounding PNES, often resisting psychological explanations. Negative experiences with healthcare professionals were common. Patients seeking validation of their experiences often reported feeling ignored or doubted. Many reported past or current stressful events. Some demonstrated insight into their methods of emotional processing. PNES were described as a significant burden associated with financial and psychosocial losses.

Conclusions: Qualitative studies have produced helpful insights into patients' experiences of living with PNES, but many patient groups (men, young people, elderly, non-Western patients) are underrepresented in studies carried out to date. Research capturing these patient groups and using new methods of data collection and qualitative analysis could help to deepen our understanding of this disorder.

1. Introduction

Psychogenic nonepileptic seizures (PNES) are episodes of abnormal experience and observable behaviour that superficially resemble epileptic seizures. Unlike epileptic seizures, PNES are not caused by epileptic neuronal discharges in the brain [1], but are usually understood as a dissociative response to potentially distressing internal or external stimuli [2,3].

There is no universally accepted unifying model of PNES aetiology, however, current evidence suggests that PNES are best understood using a bio-psychosocial approach [4]. As, there may not be a single factor or mechanism that explains PNES in all patients. Instead, a range of different interacting causes may contribute including: predisposing factors, such as a previous experience of significant trauma or conflict; precipitating factors occurring just prior to the onset of the seizure disorder; perpetuating factors that make it difficult to take control of seizures; and triggers, which occur before individual events [2,5].

When compared to healthy populations or patients with epilepsy, those with PNES report higher rates of psychiatric problems including somatoform, dissociative, anxiety, mood and personality disorders [4,6–10]. Patients with PNES also exhibit a higher prevalence of alexithymia traits [11,12] and other emotional processing impairments [13,14]. Psychopathology and significant impairments of functioning associated with PNES are reflected in a lower health related quality of life [15]. Despite the fact that in the current medical thinking PNES are conceptualised as reactive or largely "psychological" [16,17], patients often reject psychological

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Table 1
List of databases and search terms. Search was performed February–March 2016.

Databases	Search terms
Web of Science, Medline via Pubmed, PsycINFO, Forum Qualitative Sozialforschung/Forum and CINAHL, Google scholar	*“nonepileptic seizures”, “psychogenic nonepileptic seizures”, “nonepileptic attack disorder”, “dissociative seizures”, “qualitative”, “pseudoseizures”* AND *“phenomenology”, “lived experiences”, “conversation analysis”, “qualitative”, “thematic analysis” “subjective experiences”, “Interpretative phenomenological analysis”*

explanations and consider their problem as at least partly physical [18–20].

Patients’ perception and subjective experience of PNES have been the subject of a considerable number of studies [17,18,20–22]. Most of these have used self-report questionnaires focusing on the seizure disorder, although some have addressed the experience of individual seizures [23–26]. Validated questionnaires can provide data suitable for quantitative analysis and facilitate comparisons between different patient groups, but they can only capture how patients have understood a particular question and may not reflect what is most relevant to the patient about their experiences of PNES. While these general points would apply to self-report questionnaire studies of any condition, the heterogeneity of PNES and the particular relevance of subjective symptoms in this disorder make it a particularly difficult problem to capture using this methodology. This means that research into the experience of PNES stands even more to gain from the use of qualitative methodologies than studies examining the illness experiences of more uniform disorders.

Qualitative methods are not only capable of reflecting a broader range of experiences, they also allow patients to communicate their feelings and thoughts in more fine-grained and richer detail compared to quantitative self-report methods. Qualitative approaches enable patients to prioritise and clarify, in their own words, what is important to them rather than forcing them to reply by endorsing pre-defined categorical responses that may oversimplify the idiosyncrasies of the condition.

Previous reviews of the PNES literature have focused on the differential diagnosis, aetiology, altered consciousness and treatment of PNES [4,27–30]. The systematic review of a body of work is a well-established approach to help identify gaps in knowledge and provide guidance for clinicians and policy-makers [31]. Syntheses of qualitative works are becoming more common and have been conducted in developmental [32], psychological [33] and organic disorders [34–36].

The purpose of the current review is to produce a systematic narrative synthesis of qualitative research investigating PNES. Our aim is to develop a broad understanding of what is known regarding the experiences of living with PNES from patients’ own words.

2. Method

2.1. Literature search

The databases and terms used for our literature search are reported in Table 1. The search strategy was continuously refined as the key terms of suitable studies were added to our existing search terms. References of suitable studies were checked for potential studies. References of any suitable studies known by the authors were added.

There is little consensus regarding how, if at all, the quality of qualitative research should be assessed [37]. Rather than using a formal quality-rating scheme and introducing potential selection bias, we included studies that were published in a journal between 1996–2016 and had thus undergone peer review. A timeframe of 20 years was chosen to capture experiences of living with PNES relevant to patients living with this problem today. We only included studies in which authors reported their approach to qualitative analysis in sufficient detail to allow others to understand the approach taken, its particular strengths and limitations. The inclusion and exclusion criteria are reported in Table 2.

2.2. Data analysis

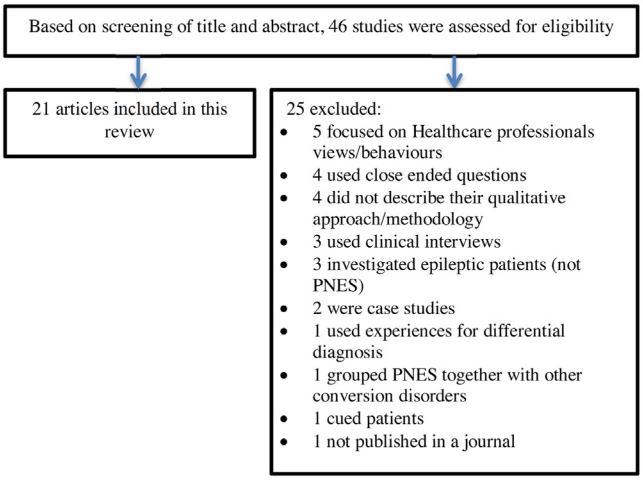
There is no definitive or ideal approach to analyse or synthesise qualitative data. Resonating with the methodology adopted by two previous syntheses of qualitative findings [32,41], we conducted a narrative review involving three stages of analysis.

Stage one involved extracting the aims, patients’ characteristics, design, methodology and findings from the studies included in this synthesis. Findings were defined as the interpretation the authors provided focusing on the patents’ experiences of PNES.

In the second stage, the findings were read and re-read allowing the researcher G.R to become familiar with the data. Initial themes

Table 2
Inclusion and exclusion criteria.

Factor	Inclusion criteria	Exclusion criteria
Aim	Focusing on lived experience of PNES from patients’ perspective	Experiences of seizures taking from sources other than the patient i.e. healthcare professionals, witnesses
Sample	Patients with PNES with and without comorbid epilepsy. No age restrictions were added.	Where patients with PNES were grouped with other conditions and PNES were not the majority
Data collection	Open ended questionnaires, interviews, collecting/analysing/interpreting patients’ own words	Case study; close-ended questionnaires and quantitative data. Clinical/diagnostic interviews and/or observations, medical and personal history interviews. There were multiple articles of this nature and whilst patients were interviewed about their experiences, Britten suggests clinical interviews and qualitative research differ in their aims. Clinical interviews aim to fit symptoms into medical categories to inform treatment and diagnosis, whereas, qualitative research does not apply constraints on the patients meanings, but instead, develops frameworks based on patients responses [38].
Data analysis	Any type of qualitative design. Reported their qualitative approach/methodology.	Studies using qualitative findings only to contribute to the differential diagnosis
Journal article	Published and peer reviewed in English between 1996–2016	Grey literature, supplements, abstracts, posters, and reports by organisations or charities. Non-English. Non-peer reviewed book chapters using qualitative methodologies to explore topics related to PNES were identified but not included [39,40]



Based on screening of title and abstract, 46 studies were assessed for eligibility

21 articles included in this review

25 excluded:
- 5 focused on Healthcare professionals views/behaviours
- 4 used close ended questions
- 4 did not describe their qualitative approach/methodology
- 3 used clinical interviews
- 3 investigated epileptic patients (not PNES)
- 2 were case studies
- 1 used experiences for differential diagnosis
- 1 grouped PNES together with other conversion disorders
- 1 cued patients
- 1 not published in a journal

Fig. 1. Flow diagram of the literature search. A table of the 25 excluded articles (including the reason for exclusion) has been included as a supplement.

and ideas were noted. Next using both a data and theory driven approach, findings were grouped by theme. It was clear from an early stage in the analysis that five main-themes emerged from the data. These main-themes were given clear titles and definitions. Within each main-theme, data was then compared and contrasted generating smaller sub-themes. This process was iterative involving moving backward and forward between the data and themes. It was at this stage the sub-themes were shared between the authors allowing for changes.

The third stage involved synthesising the data for each theme. Whenever possible, the words of the authors of the different papers and/or patients' own words as cited in these papers were used when discussing sub-themes. In this review, '' represent authors' quotations whereas "" are used for patients' own words.

3. Results

3.1. Literature search

Fig. 1 shows a flow diagram outlining results of the literature search. Twenty-one studies were included in this review (see Table 3).

In total, over 220 patients with PNES were reported (excluding Schwabe et al., who summarised their findings in >110 patients with epilepsy or PNES without providing precise patient numbers [60]; patients whose experiences were analysed in more than one study were only counted once). In keeping with the results of epidemiological studies of PNES [28], the majority (75%) of participants in the included qualitative studies were female. The mean age calculated from the 11 studies providing this information was 35.9. Fifteen studies reported the age range of patients, providing a total range of 14–75 years. Studies were predominately conducted in Western societies (the United States and European countries); two were conducted in South Africa. The rate of publication of qualitative research about PNES increased over the 20-year review period; 90% of the studies discussed were published in the last ten years.

Approaches to gather qualitative data included interviews (13 studies) and the recording of routine clinic interactions between doctors and patients (eight studies). Qualitative analytic approaches also differed, the most common being, conversations/metaphorical/linguistic analysis (seven studies), thematic analysis (five studies), and analyses based on phenomenological theory (six studies).

Five themes and 24 sub-themes emerged from the data. The five themes reflected experiences of: seizure events, diagnosis, treatment and management, emotional events, and impact on daily life (see Table 4).

4. Theme 1: seizure events

Given that the manifestations of PNES superficially resemble those of epileptic seizures, a number of studies compared subjective accounts of these two patient groups to explore whether patients' report of their subjective seizure experiences could contribute to the differential diagnosis (as well as a better understanding of PNES). When talking about their seizures, patients with PNES differed from those with epilepsy [44,59,60]. German-, English- and Italian-speaking individuals with PNES were found to volunteer very little information about subjective seizure symptoms. Patients would often resist the interviewers attempts to focus on specific seizures. When patients did discuss their seizures, statements were limited, repeated, and often restricted to holistic negations ("I know nothing") or focused on lost sensations ("I couldn't hear"). In comparison, those with epilepsy tended to volunteer more information about their seizure symptoms and actively formulate narratives of their experiences. For example, they would try hard to fill any gaps in their recollection related to episodes of loss of awareness by using perspectives of witnesses and reworking or reflecting on what must have happened. In contrast, patients with PNES would name gaps in awareness without volunteering contours (the last or next thing they remember) and without making any effort to reconstruct what happened during their seizures.

Neurologists have distinguished between four different states in the lives of people with seizures: ictal, inter-, pre- and post-ictal [63]. Cornaggia et al. [44] reports that patients with PNES are not always able to identify these phases suggesting that, in PNES at least, this division may be artifactual. Notwithstanding this, we are using these phases to organise our synthesis of information from the studies included in this review although these categories are not derived from patients themselves.

4.1. Pre-ictal

Not all patients are aware of PNES warning signs (statement 1). For those who are, seizures are often preceded by 'strong emotions', such as "fear" [51]. The amount of reported control over seizures varied from being able to take some control, 'prepare if they felt an episode was imminent', and "no control" highlighting seizures can be 'unpredictable' and 'uncontrollable' [46,47,51,61]. The inability to identify warning signs would make 'it impossible for patients to gain a sense of control' over their seizures [62].

4.2. Ictal

Green et al. explains patients provided a 'complex' and 'confusing' account of seizures, however, the most 'outstanding feature' was the variability in seizure experiences between patients [47]. While some explained a 'total lack of emotion' [51], others reported a negative "horrible" emotional impact. Thompson et al. reported that seizures can have 'an unreal, strange quality' (statement 2) and that patients may talk about them as if they felt 'overpowered' and 'trapped' [61].

As discussed, some patients avoided talking about their subjective PNES experiences. While patients may have a degree of control over how much to disclose to the interviewer, they are less likely to exercise choice over how they discuss their symptoms. Plug et al. demonstrated that, compared to patients with epilepsy, patients with PNES tended to use different

Table 3
Summary of included qualitative studies (mean age given unless otherwise stated).

Primary author, year	Country	Patients	Design	Methodology	Aim(s)
Baxter [42]	UK	$N = 12$, 8 females, age 35.5, age range 19–54, reported time since PNES onset 4.3 years (mean) 1–18 years (range)	Semi-structured interview lasting 45 min–1 h	Thematic analysis	To provide insight into patients perceptions of PNES following a psycho-educational intervention
Carton [43]	UK	$N = 84$, 65 females, age 35.2, age range 16–64, age of seizure onset 23 years (mean) 3–50 years (range), duration of attacks before re-diagnosis 10 years (mean) 1 month to 41 years (range), reported seizure frequency 26 episodes per month.	Semi-structured telephone interviews lasting on average 20 min	Content analysis	To examine patients understanding and reaction to the diagnosis of PNES and how this affects outcome
Cornaggia [44]	Italy	$N = 5$ PNES, 3 females, age 27.8, age range 17–55, duration of illness 6 years (mean) 1–11 years (range), monthly seizure frequency 2.5 (mean) 0.5–10 (range) $N = 5$ epilepsy, 4 females, age 48.4, age range 31–69, duration of illness 26.8 years (mean) 14–40 years (range)	Interview	Conversation analysis	To investigate how Italian speaking patients describe seizures
Dickinson [45]	Canada	$N = 5$, 3 females, age range 30–50+, delay to a definitive diagnosis was 2.5 years (mean), weeks to 9 years (range)	Semi structured interview	Thematic content analysis	To examine how patients make sense of their illness experience in light of the many obstacles when seeking treatment
Fairclough [46]	UK	$N = 12$, 9 females, age 43.8, age range 17–64, time since onset 9.1 years (mean) 1–35 years (range), time since diagnosis 5.1 months (mean) 3–10 months (range), seizure per month 8.3 (mean) 1–32 (range)	Semi-structured interviews	Thematic analysis	To understand perceived treatment needs and expectations in patients awaiting psychological treatment
Green [47]	UK	$N = 9$, 5 females, age 43.6, age range 30–65, age at which episodes started 35.4 (mean) 11–57 (range)	Semi-structured interviews, lasting on average 40 min	Interpretative phenomenological analysis	To explore illness representations/ beliefs of PNES using the self-regulation model as a framework
Karterud [48]	Norway	$N = 10$, 6 females, age 27.3, age range 16–61, duration from onset until PNES diagnosis 4.5 years (mean) 2–13 years (range), seizure duration few seconds to more than 1 h	Semi-structured interviews lasting approx. 50 min	Systematic text condensation—a psychological phenomenological approach	To investigate perspectives and understanding in those previously diagnosed with epilepsy
Karterud [49]	Norway	$N = 11$, 11 females, age 18.5, age range 14–23, age at first seizure 16.5 years (mean) 14–21 (range), age at diagnosis 18 years (mean) 14–23 (range)	Semi-structured interviews lasting on average 65 min	Systematic text condensation—a psychological phenomenological approach	To study the impact of using a bio-psychosocial approach to explain the diagnosis of PNES
Monzoni [50]	UK	$N = 20$ (17/20 had PNES), with PNES 11 females/6 males, age 41.8, age range 20–75	Outpatient consultant interviews	Conversation analysis	To analyse patients conversational behaviours in outpatient clinical neurology appointments
Pick [51]	UK	$N = 15$, 10 females, age range 20–50s, time since PNES onset 107.3 months (mean) 15–276 (range)	Semi-structured interviews lasting between 30–90 min.	Interpretative phenomenological analysis	To explore understanding and perceptions of: emotional functioning; emotional contributors to PNES; and alexithymia
Plug* [52]	UK	$N = 13$ with PNES, 10 female, age 34.4 age range 22–54, duration of seizure disorder 11.4 years (mean), 0.1–39 (range), monthly seizure frequency 30.5 (mean) 2–120 (range) $N = 8$ with epilepsy, 2 female, age 37.4 age range 20–67, duration of seizure disorder 19.5 years (mean), 1–38 (range), monthly seizure frequency 100.1 (mean) 1–300 (range)	Semi-standardised interview lasing between 15–30 min—outpatient consultant interviews	Linguistic analysis	To investigate the different use of seizure metaphors
Plug* [53]	UK	$N = 21$ (13 with PNES, 8 epilepsy)	Semi-standardised interview lasing between 20–35 min—outpatient consultant interviews	Linguistic analysis	To analyse the use of diagnostic labels, seizure, attack, fit and blackout
Plug* [54]	UK	$N = 21$ (13 with PNES, 7 with epilepsy, 1 unclear)	Outpatient consultant interviews—lasting approx. 30 min-	Analysis of metaphorical expression	To describe the range of metaphorical expression patient's use when discussing their seizure experiences.
Pretorius+ [55]	South Africa	$N = 10$, 8 females, age 39.2, age range 19-55, seizure frequency ranged from > once a day to none, onset of seizures to diagnosis of PNES ranged from 0 to < 7 years	Semi-structured interviews	Thematic analysis	To explore what challenges patients with PNES in South Africa face and the various coping strategies and resources available
Pretorius+ [56]	South Africa	$N = 10$, 8 females, age 39.2, age range 19–55, onset of seizures to diagnosis of PNES ranged from 0.5 years to >7 years	Semi-structured interviews	Thematic analysis	To examine subjective experiences of patients during diagnostic process
Robson* [57]	UK	$N = 13$ with PNES, 11 females, age 32, age range 23–55, duration of symptoms 8 years (mean) 0.5–17 years (range), frequency per month 14 (mean) 0.5–120 (range) $N = 7$ with epilepsy, 2 females, age 46, age range 25-67, duration of symptoms 17 years (mean) 2–38	Semi-standardised interview lasing on average 25 min—outpatient consultant interviews	Content analysis	To investigate linguistic features, namely the nature to which patients refer to and how they use third party References

Table 3 (*Continued*)

Primary author, year	Country	Patients	Design	Methodology	Aim(s)
		years (mean), frequency per month 24 (mean) 1–300 (range)			
Robson [58]	UK	*N* = 8, 8 female, age range 18-65, PNES onset 10.6 years (mean) 1–20 (range)	Outpatient consultant interviews lasting 24–58 min	Critical discourse analysis	To investigate the naming and explaining of PNES in consultations
Schwabe* [59]	UK	*N* = 6 with PNES, 6 female, age 26.7, age range 24–55, duration of seizure disorder 9.5 years (mean) 2–17 (range), monthly seizure frequency 27.3 (mean) 2–120 (range) *N* = 5 with epilepsy, 1 female, age 44.6, age range 32–66, duration of seizure disorder 22 years (mean) 4–38 (range), monthly seizure frequency 110 (mean) 6–300 (range)	Consultant interviews lasting between 20–30 min	Conversion analytic approach	To investigate how patients with PNES describe their seizures
Schwabe [60]	Germany	>110 doctor–patient encounters	Consultant interviews	Linguistic analysis	To use linguistic analysis to differentiate between PNES and epilepsy
Thompson [61]	UK	*N* = 8, 8 females, age range 20–60s, number of years since PNES onset 10.6 years (mean) 1–21 years (range)	Semi-structured interviews	Interpretative phenomenological analysis	To explore experiences of receiving the diagnosis of PNES
Wyatt [62]	UK	*N* = 6, 5 females, age 47.3, age range 29–55, time since PNES onset 13.8 years (mean) 2–44 (range), time since diagnosis 2.8 years (mean) 1.5–5 (range)	Semi-structured interviews lasting between 50–80 min	Phenomenological approach	To explore experiences of engaging in psychological therapy and adjusting to the diagnosis of PNES

*,+ Same patient sample investigated across studies.

metaphoric conceptualisations when talking about their seizures, perhaps reflecting differences in subjective experiences. They found that 80% of 382 metaphoric expressions relating to seizures could be categorised into three conceptualisations: seizure as an event/situation ("I let it run its course", "when I came out of the seizure"), seizure as a place/space ("I would drift off", "coming back") and seizure as an agent/force ("the seizure takes hold", "seizures come"). The two patient groups did not differ in the number or range of metaphors used, however, patients with PNES were five times more likely to use metaphors consistent with seizures being experienced as a space/place the patient travelled to or through than those with epilepsy who preferentially conceptualised their seizures as an agent/force or event/situation. Notably, the linguistic agency in the seizure conceptualisation preferred by patients with PNES was with the patient, whereas the seizure tended to have linguistic agency in those preferred by patients with epilepsy [52,54].

Cornaggia et al. investigated metaphorical expressions used by Italian patients and suggested that patients with PNES tended to localise the origin of their seizures within 'themselves' whereas those with epilepsy discussed themselves as 'fighters' against an 'external entity or threat' [44], observations consistent with the findings by Plug et al. [54].

Taken together, this suggests epileptic seizures tend to be experienced by patients as an external entity, impacting upon the individual. The seizure is an external opponent moving towards or away from the patient. In PNES however, the patient tends to perceive themselves as the actors and a seizure is a mental state they find themselves in. Although patients' explicit statements tend to stress the loss of control during seizures, their use of metaphors suggest that they may have some influence over the course of the seizure i.e. over their behaviour during PNES [54].

4.3. Post-ictal

The studies reviewed here demonstrate that patients with PNES preferentially focus on the consequences rather than the ictal symptoms of their seizures. Patients described a range of consequences of seizures including: "fatigue", 'frustration', "weeping", 'feelings of relief following the seizure' (statement 3) [51] and physical injuries, such as 'bruises' and 'broken bones' [43,55]. If a seizure occurred after a period of being seizure free, patients explained that this felt like a step back [62].

5. Theme 2: diagnosis

5.1. Getting the diagnostic label

Patients discussed the lengthy process of getting diagnosed [45,48]. Having to go through a variety of medical investigations was associated with feelings of 'frustration', "limbo" or being "dumped" [61,62]. This was a particular concern to patients in South Africa due to limited medical insurance [56]. Some explained getting the diagnosis was 'meaningless' [61,62]. Patients reported feeling 'disappointed' and that "it was like coming back to the beginning again" [48]. Others embraced getting the diagnosis as it 'granted legitimacy to their experiences' [62] and 'facilitated a further search for information' [46]. Some were relieved because it meant there was nothing more sinister [48,61], such as epilepsy (statement 4) [43].

5.2. Communication of PNES

Patients reported struggling to retain information when the problem was first explained to them (statement 5) [43,62]. The initial explanation was often perceived as 'limited and difficult to make sense of' [46,55]. Many patients felt confused [48,61,62], in disbelief and struggled to take in what the doctor was saying. Patients would leave with many 'unresolved questions and uncertainties' [42,48]. Being given a variety of teaching, interviews, written materials and providing opportunities to ask questions was deemed useful [42,49].

Karterud et al. examined the impact of using the biopsychosocial model to communicate the diagnosis. Patients who had received this sort of explanation stated that the holistic approach allowed them to see the multiple factors at play between 'body, mind and environment' [49]. In other studies, some struggled to see how the explanation of the diagnosis was relevant to them [61,62] and that a psychological explanation did not fit their lack of past difficulties [46].

Table 4
Example of quotes from sub-themes, S = statement.

Theme	Sub-theme	S	Typical quotation and reference
Seizure events	Pre-ictal	1	"If I knew before that would be better, but I only know after when I've had one" [62]
	Ictal	2	"· · ·Like altered consciousness"; "it was like a cartoon movie that had been slowed down, that's how I felt"; "It wrecks your life" p. 510 [61]
	Post-ictal	3	"I used to feel exhausted [after a seizure], but it was almost like all that fear had gone, almost like a relief feeling, funnily enough, that is has gone" p. 9 [51]
Diagnosis	Getting the diagnosis	4	"I love the diagnosis, because that means there's no brain damage . . . it's just psychological"; "So what's caused me to have the seizure if nothing's reminded me of any trauma in my past?· · ·It just doesn't make sense" p. 510 [61]
	Communication of PNES	5, 6	"I don't remember much [of the explanation]" p. 802 [62]; "In a way, yes, I am pleased it's not [epilepsy] but in another way I think I've got epilepsy. I don't think it's non-epileptic at all, but then again, I'm not a professional" [47]
	Misdiagnosis	7	'First they said it was epilepsy, so I accustomed myself to that, but the next time, 3 months later, they said it was psychiatric'[a] p. 42 [48]
	Reaction towards the diagnosis	8, 9	"I couldn't get my head round it, I couldn't understand, because I've never heard of anything like that" p. 298 [46]; [denies any stress citing possible] "pressure on the brain" p. 334 [47]
	Terminology	10	"Seizures is just something that I just call them just so that I can say what they are really" p. 510 [61]
Treatment and management	Encounters with healthcare professionals	11, 12	[The neurologist] "Made me feel every different than anyone else had . . . he is interested, and that felt really good" p. 511 [61]; "It just reaches a point where you just think you're [professionals] not listening to a word I'm saying" p. 300 [46]
	Validation of symptoms	13, 14	"But you know you're suffering with something. But it's like they're saying 'well no you're not, go home, go and get on with it"' p. 300 [46]; " . . . but I haven't had any of them lately because he's [her husband] always there ((laughs)) for me" p. 799 [57]
	Psychological treatment	15, 16, 17	"I'd have thought what a load of rubbish, but because you trust them and think they're obviously not doing it for fun, I'll give it a try" p.803 [62]; "We'll I don't think it's going to do any harm" p. 299 [46]; "I just can't wait to start . . . get ball rolling . . . treatment and things" p. 510 [61]
	Goals of therapy	18	[Therapy is an opportunity to] "learn to be more in control of my life and accept the diagnosis" p. 291 [43]
	Anti-epileptic drugs	19	"They increased [drug treatment] it again last week. They have to . . . find the right dosage" p. 457 [45]
	Coping	20	"And what I found is, reading the information, it was quite useful to see I'm not the only person who suffers non-epileptic seizures. There's quite a lot of people that do" p. 489 [42]
Emotional events	Stress or trauma	21	"I've had so many things happen, to me, during my life . . . " p. 9 [51]
	Processing emotions	22	"I think, one of the things about my family life, and my upbringing, was that very strong emotions are not ok, and they're not shown. Which I guess ties into the seizures in some way" p. 8 [51]
	Negative emotions	23	"Attacks make me more subdued because I am scared people will laugh at me, consequently my social world had diminished" p. 290 [43]
	Positive emotions	24	"I wouldn't say I've ever felt really happy· · ·I wouldn't say, for the past like 15 to 20 years, I've been happy," p. 8 [51]
	Hope and fears about the future	25	"Its not like you're young when you're going to grow out of it; I seem to be growing into it" p. 335 [47]
Impact of PNES on daily life	Burden	26	"My children are the other issue. Because· · ·I tried to hide it from them for a very long time· · ·I can't handle it at all, because I am the mom and they are the children" p. 36 [55]
	Family and friends	27, 28	"He even like, you know like you do with a child, 'don't walk on that side of the road', he's at it, 'mum walk on this side of the road'. He's quite protective that way" p. 298 [46]; "Without me husband ((laughs)) I never go anywhere else without him" p. 798 [57]
	Recluse	29	"So I kind of withdraw, I don't phone call, I don't pick up my phone, I don't go out, I just stay in my room . . . it can go on for days· · ·I tend to . . . shut down" p. 10 [51]
	Employment	30	"I got up to work in a charity shop for a day, well half a day, and I've started cleaning the church for half a day . . . so life is good at the moment" p. 804 [62]
	Loss	31	"Cos I used to be "boom" [punches air with hands] . . . but since all this, it just kicked a lot more stuffing out of me than I tend to realise" p. 510 [61]

[a] Typical statement.

Using Conversation Analysis on recordings of actual explanations of the diagnosis, Monzoni et al. reported that most patients exhibit resistance to the doctors' psychological accounts of their disorder. Investigating communication behaviours during 20 consultations with patients with functional neurological symptoms (of whom 17 had PNES), 15 patients exhibited overt resistance (outright rejecting the doctors explanation) and 18 patients demonstrated passive resistance (not engaging with the doctor's explanation, for instance by remaining silent instead of producing reception tokens). Patients varied in the level of their resistance from total rejection to undermining the diagnosis or treatment suggestions by asking for more tests (statement 6) [50]. In another study, examining recordings and transcripts of clinical encounters, patients were perceived to be 'defending themselves' because they seemed to interpret the doctor as making 'accusations' when explaining the link between psychological factors (i.e. being 'anxious', apprehensive) and the aetiology of PNES [58].

5.3. Misdiagnosis

Carton et al. conducted a telephone interview study one to seven years after patients had been informed of the diagnosis of PNES to investigate their reactions to and understanding of the diagnosis. All patients (n = 84) had been previously diagnosed with epilepsy. 'Almost two thirds stated they agreed with the revised diagnosis' [43]. In another study, patients who were not convinced about the diagnosis of PNES reported feeling in "no man's land" and 'lacked confidence in the new diagnosis' (statement 7) [46]. A change in diagnosis was associated with 'confusion' [43] and strong emotions, such as 'feelings of being a fraud' [47], 'anger' 'guilt' [61], and being "cheated" as patients had put restrictions on their lives [43]. Patients described feeling 'abandoned to cope' after having received the diagnosis of PNES [48]. Some, however, expressed more positive feelings; being able to "start afresh as a normal person without tablets and the stigma of epilepsy" [43].

5.4. Reaction towards the diagnosis

The majority of patients had no knowledge of PNES prior to diagnosis. The diagnosis was associated with feelings of 'shock', 'confusion' and 'anger' (statement 8) [42,43,45,46]. A common theme among patients was 'disbelief' or 'uncertainty' about the diagnosis [42,46,61,62]. Many resisted the diagnosis as a result of ideas about mental illness – believing 'seizures could not be caused by a psychological condition' [55] – or not seeing themselves as mentally ill [49].

Some patients remained confused about the nature and cause of PNES after health professionals had explained this diagnosis to them [43,47,48,61]. Some patients made contradictory remarks making both psychological and organic references when discussing aetiology [47,62]. Many patients continued to harbor the belief that the cause was organic in nature, such as a head injury [47] or epilepsy (statement 9) [43,45,62].

Disagreements with healthcare professionals were linked to 'lack of trust' and the diagnosis could become a 'subject of defiance' rather than a joint investigation of the symptoms' [48]. Adverse reactions to the communication of the diagnosis were apparent in the conversations studied by Monzoni et al. [50]. Interactional resistance from patients was less evident during the phases of the interactions in which doctors named the diagnosis or explained test results. These topics are in the epistemological domain of the professional. However, resistance was more marked when doctors attempted to make psychosocial attributions, for instance, by linking events in the patients' life with their PNES. Patients could challenge such attributions more easily by denying the traumatic nature of a particular event.

5.5. Terminology

Many patients were 'uncertain what to call the condition' (statement 10) [47]. In a study based on audio/video recordings and transcripts of real doctor-patient encounters, Plug et al. demonstrated that many patients with PNES exhibit some degree of interactional resistance to use the term "seizure". During a consultation with a neurologist, patients with epilepsy used the word seizure a mean of 9.5 times. In similar encounters, the same word was only used 4.3 times by individuals with PNES. Some patients used the term "seizure" in combination with comments like "or whatever you want to call them". Of 13 patients with PNES, five did not use the word "seizure" at all and six did not self-initiate its usage [53].

6. Theme 3: treatment and management

6.1. Encounters with healthcare professionals

Some patients reported positive encounters with healthcare professionals that were 'highly valued' (statement 11) [62]. Patients shared a sense of relief when professionals were 'pleasant', 'approachable', 'understanding', 'attentive' and 'took the time to answer questions' [45–47,49,56,61,62]. A good healthcare professional 'proved to be a significant resource to enable coping and resilience' [55]. Unfortunately, negative experiences were common [47] and expected [61]. Patients main concerns were feeling their voice was not heard and not being taken seriously (statement 12). This would result in feelings of anger and them disengaging from treatment [45,46,48,49]. Patients explained feeling that healthcare professionals were 'unwilling to compromise or appreciate subjective knowledge' [62]. This left patients with the feeling 'they had to comply with the professionals' wishes' [46].

6.2. Validation of symptoms

Some expressed the belief that PNES remain an "enigma" to the medical community [46]. Across several studies, patients discussed a perceived lack of understanding or disbelief by professionals (statement 13) [46,47,49,55,56,61,62]. While some patients explained that the doctor played a large role in 'convincing' them PNES are 'real' [55], others felt it was necessary to convince their doctor their seizures are genuine [58].

During consultations patients would tend not to answer direct questions regarding their seizure, and in many incidences divert the answer to witnesses [44]. Robson et al. examined the nature of these 'third party references' in consultations with a neurologist. Such communication patterns can yield important emotional and psychological insights. For example, introducing third persons experiences could be used as evidence to further support the point the patient is making. Compared to patients with epilepsy, those with PNES made the same number of references to others not present during the interaction (third party references), but these differed in their purpose. Twelve out of 13 patients with PNES used third party references to catastrophise their seizure experiences compared to one out of seven patients with epilepsy. In contrast, six out of seven patients with epilepsy made normalising references compared to only two out of 13 patients with PNES [57]. Patients with PNES may catastrophise their experiences to highlight the severity of the condition and to reinforce the assertion that it is not made up.

6.3. Psychological treatment

Wyatt et al. reported patients viewed the referral to psychology as indicative of mental health difficulties and worried about the consequences of attending. Patients explained therapy as 'powerful but hazardous'. For example, whilst acknowledging the benefits of 'opening up' and expressing emotions, patients were anxious therapy would be 'too reveling' [62]. For others, it was a "low-risk strategy" which they could disengage from if they found its 'aversive or not beneficial' (statement 14–16) [46]. Some expressed doubt whether treatment would work [61] or about the 'treatability of the condition' but had "no other option" [46].

Patients expressed concern and 'extreme anxiety' over therapy ending. People responded to this differently; some wanted the sessions to "taper off" gradually whilst others finished therapy early after acquiring insight into their symptoms and practical management skills [62]. Trust was seen as important [62]; building a rapport [55] and having a sense of being believed gave some patients the courage to engage in therapy [61].

6.4. Goals of therapy

Patients expressed a mixture of ideas about what they wanted from therapy. This included 'getting answers' [42], the desire to 'return to normality', to become "seizure-free", emotional release [46], to discuss problems [62] and accept the diagnosis [43]. Gaining a sense of control over their bodies, seizures and lives was an important theme (statement 18) [62]. Patients reported a 'static quality' to their life since the seizures started and 'did not feel able to move on until they understood the cause' [61].

Patients did discuss the positive effects of therapy—this was not just a reduction in seizures [47,62]. Patients reported therapy helped them feel normal, change their perspective of seizures and learn coping methods [62]. Others however reported therapy having been of no benefit, for example, because they were confused about what the 'therapist was doing and how it had any relevance' to their seizures (statement 14) [43,62].

6.5. Anti-epileptic drugs (AED)

A large proportion of patients was taking or had previously taken AED's. Some patients expressed that medication had been 'helpful' [47], for example, 'seizure control could be a matter of better drug management' (statement 19) [45]. Medication seemed to confuse patients as in some cases prescriptions were continued as treatment or a precaution after the diagnosis of PNES had been explained [45,61]. Some patients perceived AED's as having reduced their seizure frequency, thus casting further doubt on the diagnosis [42,43].

6.6. Coping

Patients discussed several coping behaviours including 'distractions', 'relaxation' [51], and 'cognitive behavioural approaches' [47]. Patients reported the benefits of peer support, sharing experiences and leaning about the disorder via the Internet (statement 20). However, some felt 'overwhelmed' by this and were unable to 'locate relevant information' [45].

7. Theme 4: emotional events

7.1. Stress or trauma

Many patients discussed past traumas [51], such as sexual, emotional and physical abuse (statement 21) [45,47,61,62]. In some patients, the relationship between the traumatic event and PNES onset lead to strong feelings of 'anger', despair [61] or weakness because something from their past was still affecting them [46].

Patients reported having experienced psychosocial difficulties. Problems included: 'conflict', 'relationship problems', 'financial difficulties', 'work-related stress', 'domestic abuse and health problems' [46,51,61]. In many cases, feelings of anxiety, panic and highly stressful events were considered by patients as having been associated with the development of PNES [43,47,48,51,62]. However, some also described joyful occasions around the time of the initial PNES manifestation [45].

7.2. Processing emotions

Some patients demonstrated insight into their methods of processing emotions, such as harboring the tendency to "bottle up" feelings [46] or 'switch off' from emotions (statement 22). Some patients went on to describe the relationship between emotional states and the manifestation of symptoms including 'pain', fatigue, and trigger factors of seizures [46,51]. Patients acknowledged the benefits of 'opening up', although they also expressed concerns about being overwhelmed [46]. Pick et al. reported patients experienced extremes of emotions including, 'weeping, aggression, destructive behaviour' [51]. In one study, a small proportion of patients (14% of n = 84) made references to 'heighted awareness or over vigilance to bodily sensations', being 'supersensitive' or 'misinterpreting benign sensations as precursors to attacks' [43].

7.3. Negative emotions

Patients expressed experiences of negative affect [62]. These emotions were 'somewhat intrusive and not within voluntary control' [51]. More specifically, patients expressed feelings of 'shame', 'stigma' or "embarrassment" about their seizures [46,48,62]. Seizures made patients feel different from everyone else, an "outcast" [46] and afraid people will 'laugh' at them (statement 23) [43]. However, not all patients discussed negative emotions, instead integrating PNES as a valid aspect of their self [62].

7.4. Positive emotions

Green et al. noted patients rarely spoke about the 'positive consequences of illness, such as spending more time with family'. Pick et al. also reported a specific 'long-term lack of positive affect' (statement 24) [51].

7.5. Hope and fears about the future

Wyatt et al. reports that in their sample (mean of 2.8 years since diagnosis, mean of eight session with a psychologist), two patients believed they would continue to manage their seizures and make positive changes. Others expressed a sense of 'passivity about the future' (statement 25) [62]. Thompson et al. reports that the patients she interviewed (average of 9.4 years since PNES onset) some talked about going through several cycles of raised hope and set backs [61]. Similarly, Green et al. reports two patients 'saw no prospect of any cure unless it transpired that all along they had a tumor' (average of 8.1 years since episodes started) [47].

Green et al. suggest patients' perceptions of their prognosis did not seem to be related to the duration of the illness [47]. Patients' understanding of PNES and beliefs about aetiology however may influence outlook. For example, two out of eight patients failed to understand the diagnosis resulting in 'outright rejection' casting doubt on the suggested treatment [61]. Similarly, Fairclough et al. demonstrated that those who acknowledged psychosocial factors were generally more hopeful for change (mean nine years since seizure onset, eight patients had experience of receiving therapy) [46].

8. Theme 5: impact of PNES to daily life

Some regarded the consequences of PNES as "very serious". Others explained it was "inconvenient" or likened the seizures to a 'physical disability', which 'was an aspects of themselves that others would have to accept' [47,62].

8.1. Burden

Patients would often describe the 'burden' that the seizures had on others [46,62]. Patients would avoid 'disclosing their difficulties' [51] due to 'concerns about burdening others, feeling dismissed or appearing vulnerable' (statement 26) [46,51].

8.2. Family and friends

Friends and family were consistently noted as a major source of support [45,51,55,56]. The negative impact of this support was also discussed, for example, patients reported that 'they often felt constrained and treated with too much caution' [45]. As a consequence, some described a 'role reversal' in 'family dynamics' (statement 27, 28) [46]. Patients spoke about the 'negative impact on their families' [42], such as 'disruptions to family life' and families often feeling 'helpless' or 'punished' [46].

8.3. Recluse

Feelings of 'isolation' [45,47,61,62] and 'lost social life' [42] were discussed (statement 29). The cause of this varied and included 'anxiety' [43], 'embarrassment' [46], and reduced 'motivation' [62]. In some, becoming a recluse was a result of avoidance coping [51]. Thompson et al. discusses the 'potential for a vicious circle of isolation' with patients becoming withdrawn and less likely to discuss their illness [61]. People viewed 'their home as the only place of true safety' [62], although being housebound could feel like a “death sentence” [55]. Whilst many agreed this was not helpful, ‘it did assist in controlling their seizures’ [62].

8.4. Employment

Inability to work was a recurrent theme with most patients feeling unable to work [42,43,45,47,55,56]. This was discussed in the context of valuing work and the associated benefits (statement 30), such as providing ‘relief from difficult life circumstances or emotions’ [51,56]. As a result of unemployment, people reported feelings of ‘grief and being on the scrap heap’ [46]. Some viewed returning to work or starting a new career ‘as a marker of their progress’ [62].

8.5. Loss

Many perceived ‘themselves and their lives’ differently [46,55,61]. Patients talked about the ‘restrictions they had placed on their lives’ which is an ‘on-going process’ [62]. Frequently cited losses included: ‘freedom’ [56], ‘independence’ [46,47,51,55,61], ‘income’ [42], ‘driving license’ [42,47,55,56], mental abilities, and ‘emotional wellbeing’ (statement 31) [46]. In the two South African studies [55,56], patients explained their ‘privacy’ was lost as precautions had to be taken to make sure they were always with someone who could protect ‘their bodily and psychological integrity’.

9. Discussion

This review synthesises the findings of 21 studies investigating subjective experiences of PNES based on patients’ own words. Using an inductive and deductive approach, five key themes and twenty-four subthemes emerged.

The first theme focuses on the wide range of experiences and symptoms associated with ictal events. The picture that emerges is consistent with studies using other methodologies to demonstrate the experientially heterogeneous nature of PNES. In interactions with the doctors, patients with PNES are more reticent than those with epilepsy to talk about their seizure experiences exhibiting ‘focusing resistance’ and ‘detailing block’ [60]. PNES have been associated with ineffective and maladaptive coping tendencies, such as an over-reliance on escape-avoidant coping [64–67]. The relative avoidance of talk of PNES symptoms may well be an interactional manifestation of avoidant coping. The fact that the avoidance of aversive emotions evident in this communication behaviour tends to diminish with successful psychotherapy suggests that it may be relevant as an aetiological mechanism [68,69].

Although PNES superficially resemble epileptic seizures, more detailed linguistic analysis reveals that the phenomenological experience of the two conditions is likely to be quite different with PNES preferentially discussed as a space/place patients travels through and originating from within. In contrast, patients with epilepsy experience their seizures as acting independently, external and sometimes hostile.

The second theme focuses on the diagnostic experience. Whilst the communication of the diagnosis is a key stage in patients’ treatment, it was not always seen as a positive milestone. There was great uncertainty-surrounding PNES with patients leaving consultations feeling confused. The problems patients describe with taking things in during the discussion of the diagnosis could be mitigated by doctors reiterating their diagnostic message in a letter to the patient, the use of leaflets, websites or by audio-recording appointments allowing patients to remind themselves later of what was said [70]. These sorts of additional communication methods could also act as external verification of the real nature of the seizures during episodes of doubt.

Psychosocial accounts of the aetiology of PNES were often strongly resisted by patients, highlighting the clear dissonance between the views of healthcare professionals about PNES aetiology and those of patients [17]. Evidence suggests patients’ illness representations can shape clinical encounters as patients may only divulge experiences they consider relevant or supporting their beliefs [71,72]. One successful approach to overcome this may be to identify patients’ explanatory models first using an open line of inquiry [73]. Previous research suggests that it is very important to deal with any conflict and/or resistance towards the proposed reactive aetiology of PNES because the effective communication of the diagnosis can have a significant effect on prognosis [74,75].

The third theme that emerged was experiences of treatment and management. Patients were concerned healthcare professionals would doubt them or not take them seriously. The impact of family members in medical decision-making has yet to be systematically studied [72], however, patients with PNES may discuss their experiences in a manner that is likely to gain validation of their symptoms. There is evidence to demonstrate neurologists believe patients with PNES have more personal and treatment control over seizures than patients themselves [17]. In contrast, patients with PNES tend to report a low level of personal control [20] and a very external locus of control [18]. Given how often patients report issues of doubt whether their seizures are real, it is clear how such misalignments in perceptions of control may cause barriers or tension resulting in poor treatment plan adherence or avoidance of healthcare contacts.

The fourth theme includes emotional experiences. Patients often discuss traumas and stress. A previous review of 17 studies states that patients with PNES report significant trauma (44–100%) and/or abuse (23–77%) [76]. Successful treatments of PNES involve the self-identification and verbal expression of emotions [16,77,78]. As such, it was interesting to find patients with good insight into their strategies of processing emotions. Having said that, in the study that reports the majority of findings related to experiences of emotional processing [51], patients were specifically directed to talk about their emotions. Watson et al. demonstrated patients with PNES are able to give more information about their sensations when given cued prompts as opposed to relying on spontaneous reporting [79]. This has clear implications for history taking, as patients may be able to provide emotional insights with prompting. Having said that, asking patients ‘loaded’ or leading question may result in patient’s saying one thing, but really believing another. This perhaps poses the question of whether patients’ responses (such as those cited in the studies discussed here) are a true representation of what they believe or feel. Healthcare professionals and researcher need to be aware of this during clinical and research interviews, and should consider using interview techniques based on very open ended questions which let the interviewee tell as much of their story as possible in their own words [80].

The final theme was the impact of PNES on daily life. Patients were conscious of the burden their PNES could place on others, leading them to withhold some of their concerns. Friends and family members were major sources of support, however, patients acknowledged that there could be too much support making them feel overprotected. Multiple experiences of loss were often discussed. These experiences highlight problems that could be addressed in psychological therapy.

9.1. Future research and limitations

While systematic reviews are a valuable method of condensing a larger body of literature and identifying gaps in knowledge, our review has some limitations. Similar to the findings of Rapport et al. who conducted a review of qualitative research in epilepsy

[81], we have identified a need to learn much more about patients' experiences of PNES outside the 'developed' world. The findings of our review are essentially limited to Europe, the United States and South Africa, and cannot readily be generalised to other parts of the world. Identifying patients' experiences from different countries (as well as those of family members and medical professionals) could help us to understand how cultural and societal influences shape the lived experiences of individuals with PNES.

All studies included in this review interviewed patients about their experiences only once, providing snapshots taken at one moment in time. While such data is useful, it is important to consider that narratives are influenced by a large number of personal and other factors. This means that, although the events in the story may remain the same, the meanings are likely to change over time as an individual develops and matures [82]. Interviewing patients over the course of their disorder could deliver different perspectives and provide important evidence for the disorders timeline and prognosis.

The methods used to gather data across all studies was limited, predominantly relying on interviews. Notwithstanding the strengths already discussed of allowing patients to use their own words, there are limitations associated with this method. Specific to individuals with PNES for example, patients often complain of loss of memory and concentration. As a result, other approaches to gather verbal and non-verbal qualitative data may be successfully applied to explore the phenomenology of PNES. For comparison, the phenomenology of epileptic seizures have been investigated using poetry [83], drawings [84,85] and writings [86]. Prompting patients about particular ictal symptoms (for instance those which are difficult to describe, such as depersonalisation, derealisation or symptoms of panic) may produce a more detailed account of seizure experiences than the open questions typically employed in qualitative research.

The patient groups included in this review have a female preponderance and were predominately drawn from adult populations. Although a number of specific risk factors have been associated with the development of the condition, PNES are a very heterogeneous disorder. As such, our conclusions may not be readily generalisable to clinically or demographically different populations of patients with PNES, even in developed countries.

Finally, although we only included studies that had been peer-reviewed and reported their approach to qualitative analysis in detail, there may be methodological limitations of this review due to the inclusion of studies using different qualitative approaches. There is no single best qualitative method, and the most appropriate method for a given question depends on a range of factors including ontology, epistemology and focus of interest [87]. These philosophical and practical factors present challenges for qualitative reviews and the best way to deal with them is debated [88]. However, the aim of this review was to produce a narrative synthesis of the lived experience of patients with PNES. Therefore, the inclusion of studies using different qualitative methodologies may also be regarded as a strength. How we comprehend an experience is a complex and diverse process, which is determined by multiple contexts, influences and factors. It follows that we cannot expect one particular approach fully to explore patients' narratives.

10. Conclusions

This is the first systematic synthesis of qualitative research studies investigating patients' experiences of living with PNES. Using an iterative process, five key themes emerged reflecting experiences of: seizure events, diagnosis, treatment and management, emotional events, and the impact of PNES on daily life. While there has been an increase in the number of published qualitative studies into PNES over the last two decades, more research is needed, especially studies focusing on patients living in non-Western countries, children and young people, and men with PNES. Future qualitative research in this field should improve our understanding of PNES by capturing patients' experiences at different points of the trajectory of their disorder and treatment.

Conflict of interest statement

On behalf of all authors of the manuscript "What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies" I declare there are no conflict of interests.

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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.2016.07.014.

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