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‘They Hear “Psychogenic” and Think, “Oh, you’re making it up”’: A Qualitative Study of Stigma and Lived Experience in People with Psychogenic Non-Epileptic Seizures

Debbie Kirby
Postgraduate MSc in Applied Psychology
Dublin Business School, Dublin, Ireland

Natalie Woodville
Lecturer School of Department of Arts Psychotherapy,
Dublin Business School, Dublin, Ireland

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Abstract

Psychogenic non-epileptic seizures (PNES) are episodes resembling epileptic seizures but without the neurological abnormalities characteristic of epilepsy. Individuals with PNES (People with PNES) live with unpredictable and disruptive symptoms, yet because the condition is poorly understood and often misrecognised, they are frequently disbelieved, invalidated, and accused of feigning illness in both healthcare and social contexts. This qualitative study explores the lived experiences of PwPNES, with a particular focus on how they encounter societal attitudes and stigma, and the implications of these for their daily life and well-being. A sample of six adults (two male, four female) with PNES took part in online, semi-structured interviews exploring their lived experiences, with a particular focus on stigma. Qualitative data were analysed using Braun and Clarke’s reflexive thematic analysis, revealing seven interconnected themes. A prominent and deeply distressing theme was participants’ experiences of having their condition invalidated or regarded as ‘all in the mind’ highlighting widespread trivialisation and scepticism. Collectively, thematic findings revealed pervasive stigma and misunderstanding, which contributed to isolation, frustration, delayed access to care, and suboptimal healthcare experiences. Concurrently, themes of resilience, community support, and adaptive coping *strategies emerged as important protective factors, highlighting how PwPNES navigate and mitigate the impact of stigma and its associated challenges. Taken together, the findings of this study highlight the urgent need for greater awareness, education, and improved diagnostic procedures to support PwPNES, while advancing understanding of their lived experience. Efforts should address both neurobiological and psychological aspects of the condition, promote compassionate, patient-centred care, and strengthen social support. This should have implications for clinical practice, policy, education, and future research.*

Keywords: Non-epileptic Attack Disorder; Stigma (Social Psychology); Medical Personnel; Patients—Experiences; Qualitative Research; Diagnostic Errors; Social Support

1. Introduction

Functional seizures, also known as psychogenic non-epileptic seizures (PNES), are convulsive episodes that mimic epileptic seizures but are thought to arise from psychological or emotional distress (Hingray et al., 2016). Like epileptic seizures, PNES are characterised by sudden and involuntary changes in motor activity, sensation, awareness, or responsiveness (Brown & Reuber, 2016; Reuber & Brown, 2017), but they occur in the absence of 'visible' structural pathology and epileptiform activity (Reuber & Rawlings, 2021; Szaflarski & LaFrance, 2018). As PNES do not conform to dominant medical models that privilege biomarkers and measurable evidence of disease, the condition is frequently construed as 'pseudo' or fabricated, undermining the legitimacy of individuals' suffering and lived experience (Myers et al., 2016; Rawlings et al., 2017; Stone et al., 2005).

PNES are characterised by fluctuating and variable symptoms which mimic those of seizures seen in epilepsy including full body shaking and episodic loss of consciousness. The highly visible disruption of seizure episodes juxtaposed with an invisible or poorly understood aetiology poses unique challenges for people with PNES (PwPNES). They are subsequently particularly vulnerable to delegitimisation and stigma. This study situates PNES in terms of epidemiology, individual and healthcare impact, conceptual and clinical challenges, and culminates in a discussion of stigma and invalidation.

1.1 Background

Living with PNES can have profound and multifaceted effects on individuals. Apart from disruption caused by seizure episodes, PwPNES often experience substantial functional impairment, along with myriad psychological, social, occupational, and fiscal consequences (Myers et al., 2016; LaFrance et al., 2008; Rawlings & Reuber, 2018). It typically presents in adolescence or early adulthood and affects predominantly female patients, with markedly high rates of psychiatric comorbidities, including depression, anxiety, and PTSD – and sometimes comorbid epilepsy (Rady et al., 2021; Reuber et al., 2003; Volbers et al., 2022, Oto et al., 2005). Seizure episodes are often unpredictable, occurring suddenly without warning. This, combined with a social misunderstanding of the nature of the condition contributes to experiences of loss of autonomy and isolation among PwPNES (Rawlings, 2017). The literature consistently reports a severely impaired quality of life among PwPNES, often to a greater extent than in people with epilepsy and other neurological conditions (Gagny et al., 2021, O'Brien et al., 2009). Prognosis is mixed and long-term outcomes are often poor: While some individuals achieve remission or symptom reduction, others experience persistent seizures and an ongoing psychiatric burden (Gagny et al., 2021; Volbers et al., 2022, Durrant et al., 2011a).

While under-recognized, the condition is not considered rare. As reported by Bompaire et al. (2021), population-based estimates suggest that PNES have an annual incidence of approximately 1.4 to 4.9 per 100,000 individuals, and a point prevalence ranging from 2 to 33 per 100,000. Epidemiological data in Ireland are lacking, though available literature estimates the incidence of PNES as being 0.91 per 100,000 people per annum (O'Sullivan et al., 2007). Within specialised epilepsy care, up to 40% of adults with drug-resistant epilepsy receive a diagnosis of PNES while an estimated 30%, who are referred to specialised services for intractable seizures, are thought to be misdiagnosed with epilepsy (Bompaire et al., 2021). A small Irish study reported that 20% of patients referred to a tertiary epilepsy monitoring unit between 2003 and 2005 were diagnosed with PNES (O'Brien et al., 2009). PNES incidence may be higher than previously recognised due to misdiagnosis (Stack, 2022), which likely reflects a poor awareness of the condition as well as broad classification and conceptual challenges.

1.2 Conceptual challenges

The history of PNES is complex and fraught with debate, particularly regarding classification and nomenclature, reflecting one of the core issues in this field (Brown & Reuber, 2016b; Reuber, 2008; Stone et al., 2002). PNES is currently categorised as a functional neurological disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2022) and a conversion or dissociative disorder in the *International Classification of Disease* (World Health Organisation, 2022).

Historically, PNES has been framed as hysteria or malingering, and terms such as 'pseudoseizures,' 'hysterical seizures,' or 'non-epileptic attack disorder' carry pejorative or misleading connotations (Rawlings & Reuber, 2018; Stone et al., 2005, Yeom et al., 2020, Edwards et al., 2012). Social and clinical discourse often continues to emphasise primarily psychological or affective underpinnings, which can result in doubt regarding the legitimacy of PNES as a 'real' condition (Foley et al., 2024). This perspective is likely reinforced by the frequent presentation of PNES with stress, trauma, anxiety, depression, and other psychiatric comorbidities (Rady et al., 2021; LaFranc et al., 2021).

Contemporary perspectives increasingly adopt biopsychosocial frameworks to explain the condition (Baslet, 2011; Brown & Reuber, 2016a). Although the aetiology remains controversial, neurobiological evidence points to functional alterations in brain networks associated with emotion regulation, motor control, and self-agency with abnormalities identified in regions including the amygdala, insula, and prefrontal cortex (Li et al., 2015; Perez et al., 2016; Szaflarski & LaFrance, 2018; van der Kruijs et al., 2012).

1.3 Clinical challenges

The aforementioned conceptual and classification challenges, combined with a poor awareness and misunderstanding of PNES, significantly complicate clinical practice and affect patient experience. The absence of consensus regarding whether PNES should be considered primarily psychiatric, neurological, or psychosomatic contributes to suboptimal management across diagnosis, treatment, and ongoing care (Reuber & Rawlings, 2021; Avalos et al., 2020; Barsky et al., 1999; LaFrance et al., 2021; LaFrance et al., 2013). The patient journey is often lengthy and disappointing: PwPNES frequently present to emergency departments, undergoing repeated admissions, unnecessary neuroimaging, and prolonged antiseizure medication use before accurate diagnosis. For example, one study found that individuals with PNES had twice as many outpatient visits and hospital admissions compared to patients with epilepsy (Duncan et al., 2011, O'Brien et al., 2009, Kholi, and Vercueil 2020; McSweeney et al., 2017). In terms of diagnosis, video-electroencephalography (vEEG) is considered the gold standard diagnostic tool, but access to such assessment is limited, with many patients waiting years for clarity (LaFrance et al., 2013; Pretorius, 2016, Jones, et al. 2021). Average diagnostic delays are estimated at 7 to 10 years, contributing substantially to excess healthcare expenditure (Kerrr et al., 2016; Reuber et al., 2002). Misdiagnosis of PNES often results in iatrogenic harm through inappropriate treatment or delayed intervention (LaFrance et al., 2013).

In terms of treatment, while pharmacological interventions such as selective serotonin reuptake inhibitors (SSRIs) are primarily used to address comorbid psychiatric conditions, there is some evidence they may also impact seizure frequency (LaFrance et al., 2010; LaFrance et al., 2008; LaFrance et al., 2021; Baslet, 2015; Reuber, 2008; Beimer et al., 2022). Pharmacological interventions, uch as anti-seizure medications, are generally not recommended for PNES, but are sometimes prescribed in cases with co-occurring epilepsy, highlighting the need for careful assessment (Spierer & Herskovitz, 2025). Evidence largely supports multidisciplinary, non-pharmacological approaches, with cognitive behavioural therapy (CBT), trauma-focused therapy, and stress management shown to reduce seizure frequency and improve coping strategies (Goldstein et al., 2010; Goldstein et al., 2020). CBT has been associated with reductions in seizure frequency, as well as improvements in depression, anxiety, and quality of life (Tilahun et al., 2021; Kanner, 2003; Kamil et al., 2019). Positive outcomes have also been reported in complex cases, including adults with learning disabilities, demonstrating that tailored CBT interventions can be adapted for diverse populations (Radez et al., 2023). Unfortunately, many care models remain limited: trauma-focused or personalised approaches are often absent, standardised outcome measures are underdeveloped (Johnsen, 2020), and transitions from inpatient to outpatient care are frequently poorly coordinated. Consequently, patients often rely on informal or online resources to fill gaps in support (Baslet et al., 2016; Kerr et al., 2018).

1.4 Delegitimization and stigma

Living with PNES involves more than seizure episodes; it entails an erosion of identity, autonomy, and social participation. The poorly understood nature of PNES makes PwPNES particularly vulnerable to stigma. Recent evidence underscores the gravity of this issue: A survey found that 76.5% of individuals with PNES reported feeling stigmatised (Karakis et al., 2020; Colombo et al., 2025).

A substantial body of literature documents that PwPNES frequently encounter delegitimising attitudes and disbelief in both social and healthcare contexts (Rawlings & Reuber, 2018; Reuber & Mayor, 2012; Thompson et al., 2009). As mentioned, in social settings individuals often report profound isolation, diminished autonomy, and withdrawal from relationships due to unpredictability of seizures and societal misunderstanding (Rawlings, 2017; Rawlings & Brown, 2017). A meta-ethnographic, systematic review by Foley et al. (2024) illustrates that delegitimation is a dominant form of stigma experienced by individuals with functional neurological disorder, the diagnostic category including PNES, and is manifest in social contexts as rejection, isolation, and workplace discrimination. Against this backdrop, some individuals find solace in online communities and advocacy groups which mitigate loneliness and offer contrary narratives to that of delegitimation (Foley et al., 2024; Szasz et al., 2025).

Overarchingly, stigma emerges as a central factor shaping individuals' experiences of their relationships and sense of belonging, and consequently, their concept of self (Szasz et al., 2025). Through repeated experiences of invalidation and stigma, individuals often internalise negative attitudes and disbelief, resulting in shame and silence. Eaves' (2024) interpretative phenomenological analysis of self-disgust in functional seizures illustrates how patients internalise negative judgements, developing feelings of being 'contaminated' or fundamentally flawed. The variable and concealable nature of the condition further amplifies identity-based stigma, in that PwPNES often do not present as ill according to conventional expectations. As O'Donnell and Habenicht (2022), and Quinn and Chaudoir (2009) argue, such processes are characteristic of concealable stigmatised identities, where the threat of exposure and invalidation continually shapes one's self-concept and behaviour. Similar patterns are observed in other concealable or 'unexplained' health conditions with poorly defined pathophysiology, including chronic fatigue syndrome/myalgic encephalomyelitis, fibromyalgia, and irritable bowel syndrome (Baloh, 2020; Kirmayer et al., 2004; Stone et al., 2005). In these conditions, invisibility and diagnostic uncertainty leave patients vulnerable to disbelief and moralising interpretations of their symptoms, positioning them as responsible for their own suffering.

In healthcare contexts, conceptual uncertainty manifests in strained patient-clinician dynamics (Reuber, 2008; Stone et al., 2005) which are further affected by patients' felt shame (Myers et al., 2022). PwPNES describe being treated as difficult, manipulative, or resource-wasting – perceptions that undermine therapeutic alliances and may result in inequitable care (Dickson et al., 2007; Kerr et al., 2016; Rawlings & Reuber, 2018). Clinicians frequently express negative attitudes towards PwPNES, and these views often persist even after diagnosis with patients describing feelings of abandonment and withdrawal of medical support once epilepsy has been ruled out (Green et al., 2003; Thompson et al., 2009). Consequently, PwPNES face protracted healthcare journeys marked by inconsistent care and lack of empathy which can exacerbate their psychological distress (LaFrance et al., 2013; Ludwig et al., 2018). This is concerning, particularly as evidence suggests that the stigma itself can heighten symptom severity, causing a self-perpetuating cycle of diminishing quality of life (Pick et al., 2019. Additionally, shame and self-disgust may function as barriers to therapeutic alliance, as patients may anticipate further invalidation and thus avoid disclosure or disengage prematurely from care (Myers et al., 2022, Schwars et al., 2022). Such findings underscore that stigma does not merely operate externally but is internalised in ways that erode identity, self-worth, and engagement with treatment.

1.5 Rationale and objectives

Taken together, the existing literature shows that stigma is a central and pervasive issue in the experience of PwPNES. Across social and clinical contexts, individuals with PNES frequently encounter disbelief, delegitimation, and negative stereotyping which amplify psychological distress, reduce quality of life, and impact socio-occupational functioning. Stigma is intertwined with conceptual ambiguities: Despite growing neurobiological evidence that PNES occupies a liminal space between neurology and psychiatry (Anzellotti et al., 2020), and is often interpreted primarily as a psychological or functional problem, all of which reinforce perceptions that the condition is ‘less real,’ attention seeking, or self-inflicted. This contributes to diagnostic delays, and inappropriate medical interventions – suboptimal healthcare journeys. Collectively, this evidence points to a pressing need to address understanding of PNES with the aim of reducing stigma.

The purpose of the present research is to contribute to the existing body of literature on the lived experiences of PwPNES, raising awareness of the condition, and specifically highlighting the impact of stigma. More specifically, the objectives of this qualitative study are:

1) To explore how PwPNES perceive and experience societal attitudes towards their condition.
2) To explore their experiences of stigma, including the impact on mental well-being.

To explore how individuals adapt to societal perceptions or stigma, seek support, and manage their mental health.

2. Methodology

2.1 Design

An exploratory, qualitative design with online semi-structured interviews was used, with data analysed using reflexive thematic analysis (Braun & Clarke, 2019). This phenomenologically-oriented study explored the lived experiences of individuals with PNES with a focus on the social and psychological dimensions of living with PNES. In particular, it examined individuals’ experiences of stigma. This approach was utilised due to its suitability for capturing the subjective experiences of each participant in depth. Ethical approval for this study was granted by the Dublin Business School Ethics Committee.

2.2 Sampling and participants

A purposive online sampling strategy was used to recruit individuals living with PNES between November 2024 and April 2025. Participants were eligible if they were adults (18 years or older) and living with either self-reported or formally diagnosed PNES. To reach the targeted population, the researcher shared the study online with various patient communities and advocacy groups on Facebook, Twitter, and Reddit. A total of six individuals (two male and four female) expressed interest and took part in the semi-structured interviews. No demographic data was formally collected.

2.3 Materials and procedure

Consenting individuals took part in a semi-structured interview conducted remotely, using the teleconferencing software Zoom. Prior to participation, individuals were provided with an information sheet outlining the purpose of the study and their right to withdraw at any stage. They were informed that the interview would centre on experiences of PNES and stigma and was expected to last approximately 45 minutes.

A semi-structured interview protocol (see Appendix A for more details) was developed and used. The interview schedule comprised 11 open-ended questions informed by the research aims and previous studies on PNES. Questions were designed to explore the challenges and coping mechanisms of individuals living with the condition, with a focus on practical, emotional, and social dimensions. The interview commenced with a broad introductory question ('Can you start by telling me about your experience with PNES?'), with subsequent questions concerning sense of identity and self-perception.

The interviews were conducted in December 2024 through April 2025 and lasted from 28 minutes to 39 minutes in duration, averaging 35. All interviews were audio-recorded via Zoom, transcribed to Microsoft Word and anonymised to ensure all personal data were moved, after which recordings were discarded.

2.4 Analysis

Transcribed interviews were analysed using reflexive thematic analysis (Braun & Clarke, 2019) via NVivo 12 software (QSR International, 2018). This analytic approach is inherently interpretative and emphasises the active role of the researcher in gleaning meaning from the data (Braun & Clarke, 2019). Accordingly, the analysis involved collaborative discussion and reflexivity throughout to ensure a nuanced and transparent interpretation of participants' accounts. To ensure academic rigour and minimise the impact of personal assumptions and biases on the research process, reflective journals were maintained by researcher DK, and the process was discussed with the supervisor on an ongoing basis.

The analytic process followed six phases and was performed by DK with interpretations and findings discussed with supervisor NW. First, the analysts familiarised themselves with the data through repeated reading and discussion of initial impressions. Second, systematic coding and categorisation were conducted by DK and subsequently discussed with NW. Third, DK organised codes into potential themes and subthemes by identifying patterns across the dataset. Fourth, these themes were collaboratively reviewed and refined to ensure they provided an accurate and coherent representation of the data. Fifth, the themes were agreed, defined, and named. Finally, the thematic findings were written up by DK.

2.5 Reflexivity

As mentioned, the research employed a reflexive thematic analysis which acknowledges the impact of the researcher's positionality and perspectives on the research focus and process. The researcher and first author, DK, holds a higher diploma in psychology and is currently working towards a master's degree with an interest in neuropsychology with previous experience of PNES and the Irish medical system. NW holds a PhD in psychology and has a special interest in qualitative research of poorly understood chronic illnesses, including functional neurological disorder.

3. Results

Reflexive thematic analysis resulted in seven interwoven themes with 13 subthemes, as presented in Figure 1 and discussed below with illustrative quotes. These themes captured the complex lived experiences of individuals with PNES. Overall, participants' accounts were characterised by experiences of disbelief, dismissal, and emotional strain alongside a persistent struggle for validation. At the heart of these narratives were negative encounters with healthcare professionals, societal misunderstanding of PNES, and a profound desire for recognition and support.

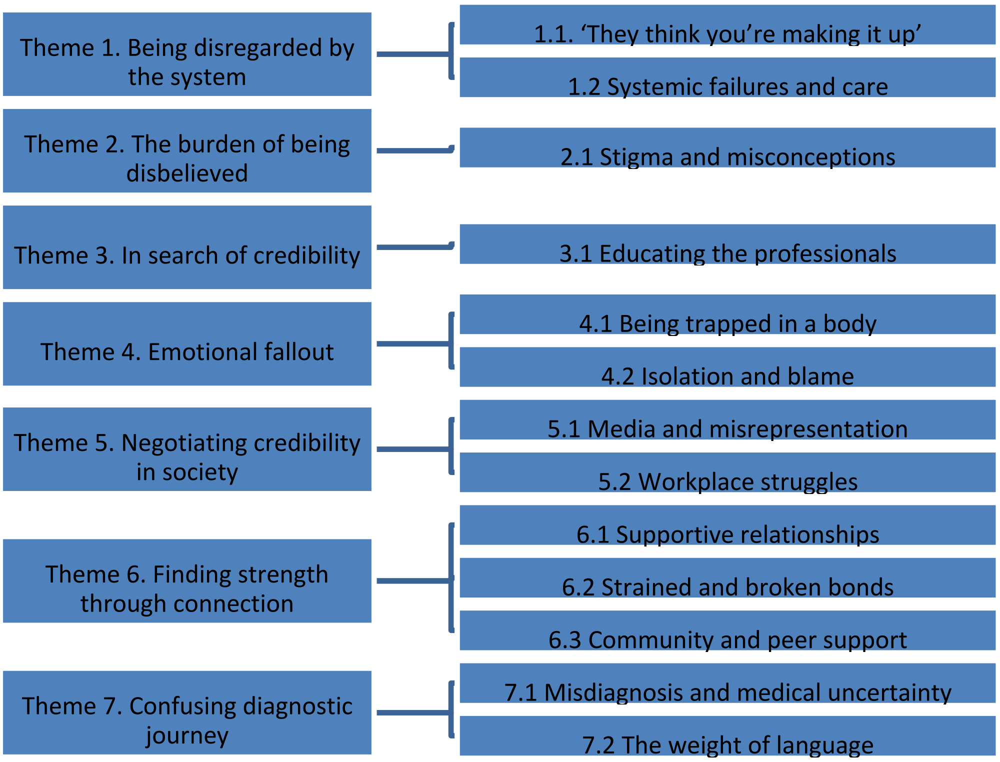

Figure 1. Thematic Findings

Theme 1. Being disregarded by the system

The first core theme concerns participants’ experiences of feeling overlooked, dismissed, or inadequately cared for within healthcare systems. Participants often described medical encounters where the introduction of the term ‘psychogenic’ shifted clinical attitudes from concern to disbelief, leaving them feeling delegitimised. At the same time, systemic barriers such as long waiting times, limited expertise, and inaccessible treatment reinforced the perception of neglect. Together, these experiences highlighted how dismissal occurs both at the interpersonal level through the attitudes of professionals, and at the structural level through institutional shortcomings.

Subtheme 1.1 ‘They think you’re making it up’

A dominant experience was the perception of dismissal by medical professionals, particularly once the psychogenic label was applied. For many, this shifted the clinical encounter from empathy to scepticism, as participants felt their symptoms were reframed as exaggerations or fabrications. This left them feeling delegitimised and profoundly invalidated. The continued use of terms such as ‘pseudo-seizures’ or ‘conversion disorder’ further compounded this, reinforcing a sense that their illness was not real. As Participant 1 summarised,

> They hear ‘psychogenic’ and think, ‘Oh, you’re making it up.’

Such encounters did not merely frustrate participants but actively eroded trust in healthcare, leaving them reluctant to seek further medical help.

> It's very hard to sit down and explain it to like a stranger or a doctor even because you feel like you won't be taken seriously and it feels really disheartening when people are like, well, do you take meds or can you take meds or what are you doing about it when there's not really anything you can do besides like get therapy and hope that it gets better? Like there's nothing more than that? (Participant 1)

Subtheme 1.2 Systemic failures and care

Beyond interpersonal dismissal, participants described systemic failures that perpetuated neglect. Long waiting lists, scarce PNES specialists, and financial barriers such as limited insurance coverage created a structural environment in which accessing care was almost impossible. Participants reported being prescribed psychiatric medication without clear explanation, further highlighting the lack of specialist knowledge. For some, this felt like a symbolic gesture of care rather than a genuine treatment plan, as Participant 3 noted,

> They were just like, 'well, here's a bunch of antidepressants.' Like, 'good luck, kid.'

These accounts suggested that systemic shortcomings are experienced not only as logistical frustrations but also as evidence of a healthcare system unwilling or unable to meet PwPNES' needs, reinforcing feelings of abandonment and marginalisation.

> I have not witnessed a single Doctor who whose bedside manner is appropriate for dealing with these kinds of patients. It's kind of disgusting (Participant 3).

Theme 2. The burden of being disbelieved

The second theme reflects the emotional and social consequences of disbelief. Participants reported being perceived as exaggerating, malingering, or seeking attention which not only shaped their clinical encounters but also filtered into their family, social, and community relationships. This disbelief was often communicated through stigmatising language and refusal to use correct terminology, producing feelings of shame, silencing, and isolation. The theme illustrates how disbelief became a pervasive burden that undermined participants' sense of self-worth and constrained their social worlds.

Subtheme 2.1 Stigma and misconceptions

Participants consistently highlighted disbelief and stigma as being central to their experiences. In both clinical and social contexts, PNES was framed as attention-seeking behaviour rather than a genuine health condition. Participant 3 described this bluntly:

> They think I'm just doing it for attention or something.

This pervasive stigma extended to language, where refusal to use the correct terminology (i.e., PNES) was experienced as deeply demeaning. As Participant 6 expressed,

> It's a seizure in every sense of the word and it's very demeaning… to tell them that it's not.

These accounts illustrate how disbelief becomes internalised, resulting in feeling shame. In turn, this social invalidation left participants feeling isolated, even within their own families where they reported rejection, minimisation, or avoidance of conversations about PNES.

> When you say psychogenic, there's just such a stigma with it. People think you're crazy That just psycho. I'm just hearing psychogenic anything to do with that word just

> automatically triggers that response and people, but trying to explain anything, any kind of mental disorder or there's, Yeah, there's judgement. Definitely. I definitely feel judgement. (Participant 6)

Theme 3. In search of credibility

Participants described a persistent struggle to establish legitimacy for their condition, particularly in medical contexts. A striking feature was the need to step into the role of educator, attempting to explain PNES to underinformed professionals. While this advocacy occasionally fostered a sense of empowerment, it was more often experienced as draining, disheartening, and unfair, highlighting the lack of institutional knowledge and training. This theme underscores the asymmetry of power in clinical encounters, where patients seek credibility in systems that offer little recognition.

Subtheme 3.1 Educating the professionals

Participants often found themselves forced into the role of educators, compelled to explain PNES to the very professionals tasked with their care. This reversal of roles underscored the lack of medical training and research, leaving patients carrying the burden of legitimising their own illness. For many, this advocacy was exhausting and disheartening:

> It's so under-researched and there's not a lot of people who specialise in PNES (Participant 6).

While some participants took pride in raising awareness, most expressed frustration that their credibility hinged on personal advocacy rather than professional recognition. This struggle illustrates a profound lack of balance between knowledge and authority, where patients sought legitimacy in a system that failed to provide it.

> I think educating yourself is a part of being a good healthcare professional and continuing to learn more. But I also think they should talk about it in school, even if it's not a lot. (Participant 2)

Theme 4. Emotional fallout

This theme captures the profound emotional toll of living with PNES, which participants described as both embodied and social. On a physical level, seizures were experienced as trapping and disempowering, leaving participants feeling disconnected from their own bodies. On a social level, disbelief and blame from others reinforced isolation and guilt. The result was an ongoing cycle of despair, frustration, and fear with participants struggling to maintain hope in the face of uncertainty.

Subtheme 4.1 Being Trapped in a Body

The emotional toll of PNES was described as deeply embodied, with participants framing seizures as imprisoning and disempowering. Seizures were not only unpredictable but also stripped participants of autonomy, leaving them feeling 'trapped' within their bodies which they could no longer trust. Participant 4 captured this poignantly:

> There have been a lot of days where I've felt very trapped in my own body.

This sense of entrapment affected not only the physical but caused emotional exhaustion, where daily life was shaped by uncertainty, fear, and loss of control.

Subtheme 4.2 Isolation and blame

The social consequences of PNES amplified this emotional burden. Participants described profound loneliness, often linked to the disbelief of others. Participant 3 noted:

> I still kind of feel like I'm alone.

Some reported being explicitly blamed for their seizures, reinforcing feelings of guilt and shame. This dual burden of internalised blame and external rejection contributed to an ongoing cycle of despair, in which participants oscillated between resilience and hopelessness.

> I'm not nearly as social as I used to be as far as like going out to places, I used to love. Do you know, go to the theatre, go to the mall, go walk around here, go to the I'm not like that anymore. I very much prefer to stay home because I feel safe at home. I know if I need to have a seizure or whatever I can get on the ground. We have dogs that are trained to like, wake me up to go get Dad. (Participant 4).

Theme 5. Negotiating credibility in society

Beyond the medical system, participants also grappled with societal misunderstandings of PNES. Media representations of seizures created rigid expectations of what a seizure 'should' look like, which contributed to disbelief when PNES presented differently. This misunderstanding extended into the workplace, where lack of accommodation and outright discrimination created barriers to employment and stability. This theme highlights how credibility was not only contested in healthcare but also negotiated in wider social and cultural contexts.

Subtheme 5.1 Media and misrepresentation

Participants linked public misunderstanding of PNES to stereotypical portrayals of seizures in film and television, where epilepsy was depicted narrowly and dramatically. When their own seizures did not conform to these expectations, disbelief followed. Participant 3 explained:

> A seizure looks like X, Y, and Z, and then you're presented with a seizure that doesn't look like that… it looks like some dramatic TV reenactment.

Such cultural scripts not only misrepresent PNES but also fuel stigma, as participants felt their condition was judged against inaccurate benchmarks.

Subtheme 5.2 Workplace struggles

Employment settings were described as particularly hostile, with participants facing discrimination, job loss, and difficulties maintaining stability. The invisibility and misunderstanding of PNES meant that workplace accommodations were rarely provided, forcing many out of jobs altogether. As Participant 4 recounted,

> I've gotten fired from a couple of jobs because I haven't been able to consistently go.

These accounts highlight how societal misunderstandings of PNES extend beyond cultural stereotypes to tangible socioeconomic consequences, exacerbating participants' marginalisation.

Theme 6. Finding strength through connection

Despite adversity, participants identified sources of resilience within their social worlds. Supportive family or friends provided validation and stability, serving as a buffer against stigma and disbelief. However, relationships were also strained or fractured, with some participants experiencing rejection or abandonment. For many, online communities and advocacy groups offered a crucial alternative space of belonging, validation, and empowerment. This theme illustrates how connection, whether supportive or absent, was central to participants' ability to cope with the challenges of PNES.

> And like I said, that's what the support groups are for. And I think it's important to hold on to the supports that you have like to find friends and family that do support you and to like to grab on to that and realise like who in my life believes me and like really kind of let that blossom more. (Participant 5).

Subtheme 6.1 Supportive relationships

Despite adversity, supportive relationships were identified as vital lifelines. Participants described trusted friends or family members as sources of validation and stability in an otherwise invalidating landscape:

> She became my number one support system (Participant 4).

Such connections not only provided emotional relief but also mitigated the psychological burden of disbelief.

Subtheme 6.2 Strained and broken bonds

Conversely, others described how PNES strained relationships, leading to mistrust, rejection, or abandonment. Participant 1 reflected,

> It wrecked my relationship with quite a few people.

This breakdown of support reinforced participants' feelings of isolation and highlighted how stigma extended into their closest social circles:

> She had mentioned to me a little bit ago that after I started having them that we, she thought about breaking up with me because it was such a big shift because I went from being like normal for all intents and purposes to like having this debilitating like order. (Participant 6).

Subtheme 6.3 Community and peer support

Online spaces and advocacy groups emerged as crucial sites of solidarity, where participants felt seen, validated, and understood. For some, these communities provided not only emotional support but also a sense of agency and purpose:

> Well, I want to help others. I want to be of help. I don't want to be one that's, you know, chanting change but not doing anything about it (Participant 1).

These peer networks functioned as counter-spaces to the disbelief of medical and social worlds, offering participants a rare sense of belonging.

Theme 7. A confusing diagnostic journey

The final theme reflects participants' experiences of uncertainty and frustration in the diagnostic process. Participants' journeys towards diagnosis were often characterised by lengthy periods of medical uncertainty and misdiagnosis, and highlighted a core issue of poor continuity of care. A confusing and often invalidating diagnostic landscape deepened mistrust toward healthcare professionals and heightened participants' sense of invisibility.

Subtheme 7.1 Misdiagnosis and medical uncertainty

Participants' experiences of diagnosis were largely negative and typically involved a lengthy cycle of referrals between different specialists. Many described being "bounced" between neurologists and psychiatrists, with little guidance regarding their prognosis or next steps in diagnosis and treatment.

Participant 1 recalled:

> Every neurologist I've seen— 'Go see someone in psych.'

This culminated in a profound sense of being dismissed and rejected by individual clinicians, as well as more broadly by the healthcare system.

> Everyone was very dismissive. That's been kind of my experience with medical professionals in general throughout my time (Participant 1).

Such accounts often reflected the invisibility of PNES within medical practice:

> And medical professionals look at that and don't know what to do with it because that's not what a seizure is supposed to look like. (Participant 6).

Subtheme 7.2 The weight of language

As previously mentioned, participants frequently characterized labels such as "pseudo-seizures" or "conversion disorder" as misleading and experienced them as invalidating of their lived experiences. They often commented on how these terms were out-dated and inappropriate, and noted that some clinicians appeared unfamiliar with or unaware of the contemporary diagnostic designation of "PNES".

> And he's he was very snarky with me from that point on, but that's problematic, that medical professionals don't even know the proper terminology because it's demeaning to not even have it called by the proper term. (Participant 4)

The weight of this extended beyond personal distress and feelings of being dismissed but was also perceived as a barrier to care. Participants noted that some clinicians interpreted the labels as suggesting a lack of seriousness or urgency, thereby impeding access to support. As Participant 6 put it,

> I need help. I'm obviously here because I want help, and I don't need you telling me that there's nothing wrong.

Language, ultimately, became both a clinical and social tool of dismissal, leaving participants mistrustful of healthcare providers and uncertain about their own condition.

4. Discussion

The present study set out to examine the lived experiences of PwPNES, with a particular focus on how stigma is perceived and experienced, its impact on mental well-being, and the strategies individuals employ to adapt to and cope with it. The rich accounts of PwPNES illustrated the often-distressing nature of living with unpredictable and poorly understood symptoms. Moreover, they highlighted not only the direct impact of seizures on their daily lives but also the emotional, social, and systemic challenges that compounded their experiences. Accounts revealed how individuals struggled with the confusing and often invalidating diagnostic journey, the heavy emotional fallout of living with a misunderstood condition, and the disbelief and invalidation they encountered in both clinical and social contexts. At the same time, findings illustrated remarkable resilience: Despite the burden of symptoms and an ongoing fight for recognition and credibility, PwPNES also identified coping mechanisms and sources of strength, particularly through supportive relationships and online communities. Taken together, the findings provide valuable insights into the multifaceted impact of stigma in social and healthcare settings highlighting a need for improved awareness, knowledge and understanding of the condition, as well as improved support systems for PwPNES.

4.1 Living with a stigmatised condition

As noted, a core finding was the profound impact on daily life, with participants reporting a marked loss of autonomy, anxiety about the unpredictability of their condition, and financial difficulties in securing appropriate care. The combination of these factors created a sense of powerlessness as individuals felt increasingly dependent on others while simultaneously unable to manage or predict the course of their own condition. This lack of control was a central theme in participants' narratives and significantly affected their overall well-being. This aligns with studies highlighting that lower perceived control is associated with poorer mental health outcomes and lower quality of life in chronic illness contexts (Connell et al., 2012; Wadsworth et al., 2020; Walther 2019; Walther, 2020).

The emotional burden of PNES emerged as a dominant thread, with participants frequently articulating experiences of guilt, hopelessness, and fear. Many described the stress of managing the condition as overwhelming, and stigma only intensified these emotions. The unpredictable and often uncontrollable nature of their symptoms, compounded by external misunderstanding, was linked to experiences of depression, anxiety, and emotional dysregulation. These mental health challenges frequently resulted in social withdrawal, as participants reported strained relationships and the loss of social connections due to misconceptions about their condition.

Coping mechanisms were varied and complex, ranging from therapy and medication to self-care strategies and engagement in online communities for support. Therapy, whether individual or in groups, was mentioned as an essential tool for some participants, helping them process the psychological trauma that often-accompanied PNES. However, participants also reported that dealing with the social stigma of their condition was a continuous challenge, making it difficult for them to fully trust others or feel comfortable seeking help. Self-care strategies such as mindfulness, relaxation techniques like breathing exercises, and pacing were also mentioned. However, their effectiveness was often limited by the unpredictability of seizures. Recent studies have similarly highlighted the benefits of therapy and multidisciplinary care in PNES management (Seyer et al., 2018; Stern, 2024; LaFrance et al., 2013), while also identifying barriers to trust in healthcare providers, including poor communication and perceived lack of expertise (Hatoum et al., 2022).

A key finding of this study underscores the significant influence of language on participants' experiences. Although considered preferable to terms like "pseudo-seizures," participants reported that the label "psychogenic", which is commonly understood as meaning "produced by the mind", was frequently misinterpreted by others to mean that PNES symptoms are imagined or under voluntary control. In their accounts, participants repeatedly expressed frustration with how psychogenic explanations of their condition were presented to them, feeling that these explanations often dismissed the legitimacy of their symptoms and invalidated their experiences. Some participants indicated that, although they could accept the psychological aspects of PNES, a focus on psychogenic explanations made it difficult to feel fully supported in treatment. It seemed that in some cases clinicians primarily concentrated on the psychological component of PNES and were inattentive to the wider complex of symptoms. Consequently, participants approached healthcare with caution, which aligns with previous research, which illustrates how such psychogenic explanations can lead to a lack of trust in the healthcare system and poorer treatment outcomes (Krámská et al., 2021; Rawlings & Reuber, 2016; Reuber, 2008, McMillan et al., 2014). Additional studies have also shown that patients often perceive psychogenic explanations as minimising their lived experience, which can reduce engagement with recommended therapies and contribute to prolonged diagnostic uncertainty (Edwards et al., 2012; Goldstein et al., 2010). Given the persistence and impact of psychogenic explanations, the results suggest a need for greater sensitivity in how PNES is communicated and managed, ensuring that diagnostic language and clinical interactions do not inadvertently reinforce stigma or undermine patient legitimacy.

Patient narratives illustrated that their interactions with the healthcare system were fraught with difficulties. Long waiting times, misdiagnoses, and financial constraints were recurrent issues. Many participants reported struggling to access specialists or experiencing delays in receiving appropriate care; this aligns with prior findings that PNES patients often face prolonged diagnostic pathways and limited specialist availability (Bodde et al., 2009; Reuber & Mayor, 2012). A common experience shared by participants was being prescribed medications such as antidepressants or anticonvulsants without a thorough and proper assessment and monitoring, for instance through long-term vEEG (e.g., Gedzelman & La Roche, 2014). Medications, often accompanied by side effects, led to further frustration and feelings of disillusionment with the healthcare system, reflecting earlier work which has shown that inappropriate pharmacological treatment is frequent in PNES due to diagnostic uncertainty (Plug et al., 2009; Reuber et al., 2003; McMillan et al., 2014). Additionally, the findings highlighted the significant role that stigma plays in patients' engagement with treatment and patient-clinician dynamics. Disbelief and delegitimating by healthcare professionals, often rooted in their misunderstanding of the condition, ultimately added more distress. Previous research has similarly shown that stigma and negative attitudes among clinicians can exacerbate psychological distress, reduce treatment adherence, and contribute to social isolation in patients with PNES and related functional neurological disorders (Dickson et al., 2007; Kerr et al., 2018; Szasz, 1982; Roze, et al., 2023). As in other research, all too often, participants were told that their symptoms were 'all in their head.'

The accounts of PwPNES also suggested an internalisation of stigma. Participants often assumed negative societal attitudes into their self-concept, which led to feelings of self-blame, shame, and fear, all of which significantly impacted their emotional health and the way they interacted with their healthcare providers. This finding aligns with existing research on concealable chronic conditions which emphasises that stigma contributes to increased distress and poorer health outcomes (e.g. Quinn & Earnshaw, 2011; Quinn & Earnshaw, 2013). Importantly, participants consistently reported that both social and medical stigma contributed to heightened stress levels, which in turn worsened or triggered seizures. In this case, the psychological distress caused by the experience of stigma along with the fear of being misunderstood or dismissed, created a cycle in which stress and stigma fuelled each other. This aligns with other research on stress-related disorders, which suggests that stigma not only exacerbates emotional distress but can also contribute to physical symptomatology (Roberts et al., 2020). Interestingly, neuropsychological research also highlights how difficulties in emotion regulation are strongly associated with higher levels of depression, stress, and anxiety in PwPNES (Testa et al., 2019; Research Gate A, 2025; Research Gate B|, 2025). An important implication of this is that interventions aimed at reducing stigma could directly improve quality of life by mitigating the distress that exacerbates PNES symptoms.

Together, these findings highlight the urgent need for enhanced psychological support and targeted interventions for individuals living with PNES. As suggested by other studies, there is a need for treatment approaches grounded in a balanced understanding of PNES, one that incorporates both psychological and neurobiological explanations (Baslet, 2011; Brown & Reuber, 2016a; van der Kruijs et al., 2012). Treatment adherence has been shown to improve when patients feel that both aspects are taken seriously in their diagnosis and treatment planning (Dimaro et al., 2014; McGonigal et al., 2019). Another important finding with implications for treatment in this study was the connection between trauma and PNES. Many participants noted that past trauma and abuse were significant triggers for their condition, consistent with previous research highlighting high rates of trauma history in PNES patients (Goldstein et al., 2010; Perez et al., 2016; Reuber et al., 2003). This underscores the need for trauma-informed approaches in treatment, where understanding an individual's trauma history is essential for providing care that is both compassionate and effective (LaFrance et al., 2013; Myers et al., 2022).

Accordingly, improving knowledge and understanding of PNES in both social and healthcare contexts emerge as a plausible strategy for enhancing patient outcomes. Many participants expressed frustration at the lack of basic awareness as well as specialised knowledge about PNES among healthcare professionals and the general public. Similar challenges have been reported in the literature on other poorly understood conditions which have historically been linked to hysteria (Asbring & Närvänen, 2002; Kirmayer & Looper, 2006; König, 2024; Engebretson, 2013). Thus, more progress in this domain is still needed.

4.1 Strengths and weaknesses

The present study has several strengths that advance understanding of the lived experience of PwPNES. First, the use of qualitative thematic analysis enabled an in-depth exploration of participants' lived experiences, generating rich and nuanced insights that would be difficult to capture through quantitative methods (Braun & Clarke, 2006; Braun and Clarke, 2019). The semi-structured interview format provided flexibility, allowing participants to share their experiences in their own terms and at their own pace, consistent with best practices in lived experience research (Smith & Osborn, 2015). Conducting interviews online also enhanced accessibility, reducing geographical and practical barriers to participation, a method increasingly recognised as effective in qualitative research (Gray et al., 2020). The reflexive approach to thematic analysis, with one researcher conducting the coding and subsequent discussion with a second researcher, enhanced sense-making and interpretation through collaborative reflection (Braun & Clarke, 2019). However, is it important to acknowledge that methodological strengths also pose a number of limitations. With regards to thematic analysis, the reflexive approach is sometimes critiqued for its inherent subjectivity, as themes are co-constructed by the researcher and shaped by their personal experiences, background and worldview Braun & Clarke, 2019; Byrne, 2022). While reflexivity is a recognised strength, it also raises the possibility that researcher assumptions and preconceptions heavily influence the interpretation of data. As mentioned, efforts were made to reduce such bias through the use of reflective journalling and regular supervisory oversight.

With regards to participant selection and recruitment, a purposive sampling strategy was employed, with recruitment primarily facilitated through patient advocacy groups. While this approach successfully targeted individuals with lived experience of PNES and ensured engagement with an informed population, it also represents a limitation as the sample may not reflect those most severely affected by the condition, particularly individuals with limited access to support networks. While this sampling approach allowed for the inclusion of diverse perspectives, and the online interview format increased accessibility, the study also involved a relatively small sample of six participants, limiting the representativeness of findings. However, it is important to emphasise that this study sought to examine lived experiences in depth; thus, generalisability was not a primary aim (see Smith & Osborn, 2015). Furthermore, demographic and health-related data were not collected, restricting insight into how intersecting factors such as ethnicity, education, comorbidity, or socioeconomic status may have shaped participants’ experiences. This can be addressed by incorporating larger and more diverse samples, gathering demographic data, and adopting a mixed-methods approach to enrich understanding of PNES experiences across different contexts.

4.2 Future research

Future research should aim to address the aforementioned limitations of this study, while expanding on its findings. For example, studies with a small sample size, but more in-depth interviewing while employing interpretative phenomenological analysis (Smith et al. 2009, Tindall, 2009) could be beneficial for a richer exploration of the different stigmas experienced by PwPNES, and in different contexts.

An interesting avenue for further research could be a longitudinal examination of how chronicity of illness relates to the impact of stigma, how individuals cope or adjust to stigma over time. Available literature highlights that quality of life remains markedly reduced among PwPNES, but this is particularly so among individuals with unremitting seizures (Ekanayake et al., 2021; Fiszman et al., 2004). Studies suggest that seizure persistence is common, with between 59% and 71% of patients continuing to experience episodes years after diagnosis (Reuber et al., 2003). Nuanced longitudinal research could therefore enrich the literature on stigma by considering the unique, age-related challenges faced by PwPNES with persistent seizures.

Ultimately, further biomedical research is needed to clarify the potential role of neurobiological mechanisms in PNES. Such research could refine diagnostic criteria, inform the development of targeted treatment approaches, and enhance understanding of the condition within clinical practice. Importantly, advancing neurobiological insights may also help reduce stigma and dismissal in healthcare systems that often prioritise demonstrable organic pathology over patients' lived experiences and self-reported symptoms. Addressing this gap is essential not only for improving clinical outcomes but also for validating the experiences of individuals living with PNES, thereby fostering more empathetic and evidence-informed care.

4.3 Implications and applications

The findings of this study carry significant implications for healthcare professionals, policymakers, researchers, and those directly affected by PNES. Given the lack of knowledge and the delegitimating experiences reported by participants, there is a clear need for improved training among clinicians. Specialised education that addresses both the psychological and neurological dimensions of PNES could enhance diagnostic accuracy, reduce iatrogenic harm, and foster more empathic care.

Equally important is the integration of psychological support into routine clinical pathways. This study underscores the value of therapy-based interventions not only for reducing symptom burden but also for strengthening coping strategies and psychological resilience. Embedding mental health services into PNES care models would ensure a more holistic response, addressing both the physical and psychosocial aspects of the condition. Furthermore, participants highlighted the value of online communities and peer-support networks, which provided accessible spaces for sharing experiences, reducing isolation, and fostering empowerment. Such communities may complement professional care by offering practical advice and emotional validation, particularly for individuals who face barriers in accessing specialist services. While further research is clearly needed, the findings also underscore the importance of advocacy and targeted efforts to reduce stigma, raise awareness, and promote understanding of PNES among both healthcare professionals and the wider public.

Finally, at a policy level, the findings could inform advocacy for enhanced access to diagnostic tools, financial support for evidence-based interventions, and accommodations for those living with PNES. Public health campaigns and educational programs would also benefit from these insights, particularly in challenging misconceptions and improving inclusivity within social and occupational contexts.

5. Conclusion

This study has drawn attention to the profound impact of PNES on those who live with it, revealing how impacts of the condition extend beyond the clinical manifestations. Participants' accounts illustrated that the burden of PNES is not only medical but also deeply social, with stigma and delegitimation shaping daily life, self-concept, and experiences of healthcare. Living with PNES often entails the loss of autonomy, uncertainty due to the unpredictability of seizures and strain in relationships, alongside financial and occupational difficulties. These challenges are further compounded by experiences of disbelief and dismissal, particularly within healthcare settings, where inadequate knowledge and delegitimating responses remain pervasive. Such findings reinforce the argument that stigma is an important driver of the PNES experience. The way the condition is conceptualised, discussed, and managed within medical and social contexts directly influences treatment outcomes and well-being. Advances in neurobiological and biopsychosocial models are valuable and needed, they must be matched by parallel efforts to address the psychosocial dimensions of the condition. Progress requires sustained advocacy, greater awareness among professionals and the public, and the development of services that treat patients with compassion and legitimacy.

Appendix A: Interview Schedule

Semi-structured interview questions

1. Can you start by telling me about your experience with PNES? How did you first come to realise that you had the condition?
2. How do you think society generally perceives PNES? *What are some of the most common misconceptions you've encountered?*
3. How have these societal attitudes affected you personally? *Emotionally, socially, or mentally?*
4. How has living with PNES affected your sense of identity or self-perception?
5. What emotional challenges have you faced because of living with PNES?
6. What strategies or coping mechanisms have you developed to navigate the emotional impact of living with PNES?
7. How do your family members or close friends perceive your condition*? Do you feel supported or misunderstood by them?*
8. Have you experienced any changes in your relationships because of living with PNES? *For example, have you felt more isolated, or have your social connections changed?*
9. In what ways have you adapted to living with PNES? *How have you learned to navigate life with the condition?*
10. Do you think cultural or societal factors have influenced how you experience PNES?
11. How do you think societal understanding of PNES could be improved? *What changes would you like to see in how the condition is perceived or treated?*

Note: Due to the semi-structured nature of the interviews, not all interviewees were asked all eleven questions. However, care was taken to address all topics with the interview participants, following the sequence above. Probing or follow-up questions, italicised, were employed where appropriate.

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