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# Qualitative systematic review on the lived experience of functional neurological disorder

Andrea Szasz (),<sup>1,2,3</sup> Anthony Korner,<sup>2,3</sup> Loyola McLean (),<sup>1,2</sup>

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<sup>1</sup>The Brain and Mind Centre, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia <sup>2</sup>Specialty of Psychiatry, Faculty of Medicine and Health, The University of Sydney, Sydney, New South Wales, Australia <sup>3</sup>The Westmead Psychotherapy Program, Western Sydney Local Health District, North Parramatta, New South Wales, Australia

#### **Correspondence to**

Ms Andrea Szasz; asza7613@uni.sydney.edu.au

# ABSTRACT

**Objectives** Functional neurological disorder (FND) is a complex disorder, recently attracting much research into aetiology and treatment. However, there is limited research on the patient's lived experience. This paper addresses this gap to ask: 'What is the subjective life experience of adult patients living with FND?'

**Methods** From 1980 to 2020, Medline, PsycInfo, Scopus, Science Direct, PubMed, CINAHL and Embase were searched for English language qualitative adult research. The disciplines used general medicine, psychiatry, physiotherapy, nursing, neurology, psychosomatic medicine and occupational therapy. The qualitative literature search included book chapters, theses, fellowship reports and conference articles as well as peerreviewed scientific journals.

The Critical Appraisal Skills Programme tool was used to assess 33 papers, with eight papers included in the final synthesis. Nine additional papers, suggested during review, were evaluated but excluded from synthesis, though incorporated elsewhere in the paper. Two authors used an integrative immersion approach to identify the literature's main themes using line-by-line and top-down methods.

**Results** Eight main themes were identified: lost, body– mind dualism, preceding stressful events, relatedness, stigma, the battle or fight, the burden and losses of the illness and trust versus mistrust. From these emerged a central overarching theme of relationally regulated selves, which posits the essence of the lived experience of FND as responding to stressful experiences within a relational, regulatory context.

**Conclusions** The prevalent themes give valuable insight into the lived experience of FND and the impact of stressors, past and present, and the relational environment in the development of and recovery from the disorder. Further research is needed to support the formulation of the patient experience and cocreated recovery pathways.

#### INTRODUCTION

Functional neurological disorder (FND) is a common neuropsychiatric condition, with a long history of name changes and stigmatisation. Historically, the aetiology of the disorder has been unclear.<sup>1</sup> There were several ideas within medicine and psychology to explain the possible causes for the development of this complex condition.<sup>2</sup> <sup>3</sup> Significant advances

# WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Before this study, there was limited integration of qualitative research on the lived experience of patients with functional neurological disorder (FND). Most existing studies focused on specific aspects of FND or particular presentations, such as nonepileptic seizures. There was a lack of comprehensive understanding of the overall patient experience across different FND manifestations, particularly regarding the origins and context of the disorder in terms of life story and relational history.

# WHAT THIS STUDY ADDS

⇒ This systematic review synthesises qualitative research on the lived experience of patients with FND, identifying eight main themes: lost, body-mind dualism, preceding stressful events, relatedness, stigma, the battle or fight, the burden and losses of the illness and trust versus mistrust. It introduces an overarching theme of 'relationally regulated selves', suggesting that the essence of the FND experience involves responding to stressful experiences within a relational, regulatory context. This study provides a more holistic view of the experiences of patients with FND across various presentations of the disorder.

#### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study highlights the need for more comprehensive qualitative research that includes patients' life stories, relational histories and significant stressors, including traumas and losses. It suggests that clinical practice should adopt a more holistic, biopsychosocial approach to FND, considering relational aspects and regulatory processes in assessment, formulation and treatment. The findings emphasise the importance of addressing stigma, building trust in therapeutic relationships and developing multidisciplinary, patient-centred approaches to FND care. This could inform policy changes towards more integrated care pathways and increased education about FND for healthcare professionals.

have been made in understanding FND's neurobiopsychological mechanisms in recent years. Current understanding of FND emphasises abnormalities in predictive processing

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and the interaction between attention, emotional processing, agency and interoception.<sup>4 5</sup> FND symptoms include motor weakness, movement disorders, loss of other sensory functions and non-epileptic seizures. Symptoms are involuntary, and the severity can vary from slight somatic concerns to severe chronic functional impairment.<sup>6</sup> FND is now diagnosed through positive clinical signs via specific neurological examinations, representing a shift from historical approaches that viewed it as a diagnosis of exclusion.<sup>4</sup>

At times a complicating factor for reaching diagnosis and providing appropriate treatment is that some clinicians and practitioners still lack resources, information, support and understanding of this disorder.<sup>7</sup> Investigating possible specific causes of symptoms is time consuming and expensive and can be similarly frustrating for patients, carers and doctors.<sup>8</sup> Successful diagnoses and treatment are also made difficult as the historical names of the disorder, such as hysteria and conversion disorder, can be perceived as stigmatising.<sup>910</sup>

Recent research has moved beyond traditional diagnostic frameworks to embrace a more integrated understanding of FND. However, by investigating patients' lived experiences, including relational experiences, possible traumas and losses, and their stories of the development of the disorder, we can potentially gain more insight and further our biopsychosocial understanding of FND.<sup>11 12</sup> This qualitative systematic literature review uses thematic analysis to address the question, 'What is the subjective life experience of adult patients living with FND?'

# **METHODS**

# Literature search strategy

There was no patient and public involvement. A comprehensive literature search was conducted to explore the qualitative studies on FND and its lived experiences, considering the disorder's various names and categories. Key search terms included 'functional neurological disorder', 'functional motor disorder', 'conversion disorder' and related terms like 'somatisation' and 'psychogenic non-epileptic seizures'. The search was focused on adult participants (18+ years), excluding child and adolescent studies.

Databases such as Medline, PsycInfo, Scopus, Science Direct, PubMed, CINAHL and Embase were searched for literature published in English from 1980 to 2020, spanning disciplines like general medicine, psychiatry and neurology, but excluding quantitative studies or those focusing primarily on the disorder's biological explanations.

The search also extended to non-journal sources like book chapters and theses. After screening for relevance and quality, 33 papers were initially found, with 17 excluded for various reasons, including a lack of focus on patient experiences or inadequate data presentation. Ultimately, two additional papers were identified from references as fitting the inclusion criteria, leading to a focused examination of FND from a qualitative perspective. Nine additional papers, suggested by reviewers, were evaluated and excluded from the synthesis, though incorporated elsewhere in the paper.<sup>7 13–20</sup> See figure 1 and online supplemental table 1 for detailed information on the excluded papers.

#### **Assessment of quality**

The Critical Appraisal Skills Programme's checklist for qualitative studies<sup>21</sup> was employed for quality assurance. Seven papers examining the patients' lived experience of FND or a related disorder as the primary focus were initially included, all high quality across the CASP domains. Two further papers were added from reference searching the removed systematic review.<sup>22</sup> The CASP checklist can be found in online supplemental table 2.

## **Data extraction and synthesis**

Included papers were transferred to NVivo to organise and examine the material using a tool-supported qualitative data analysis method.<sup>23</sup> The material was organised, and data were extracted for sample size, gender of participants, location of the study, methodology and type of disorder explored in the study (see online supplemental table 3).

# RESULTS

The focus of the papers concerning the lived experience differed widely. For example, one focused on what agency meant to participants,<sup>24</sup> while another concentrated on how participants made sense of their diagnosis.<sup>25</sup> It was also clear that there was a lack of in-depth studies available exploring the lived experience of those suffering from these disorders and maintaining a broad scope. Little attention was paid to the disorder's origin, life story, relational history, and traumas and losses. Most studies focused on the lived experience of people with the diagnoses of FND, that is, the lived experience after the diagnosis.

# **Phenomenological analysis**

Phenomenological analysis, specifically interpretive phenomenological analysis, was used in three studies to explore the lived experiences of FND through semistructured interviews.<sup>24–26</sup> Another study presented a hermeneutical phenomenological view, offering a first-person account of conversion disorder through self-reflective journals.<sup>27</sup> These studies highlight the significance of individuals' embodied experiences and their process of contextual meaning making. For instance, Phoenix<sup>24</sup> examined how men with conversion disorder perceive their agency, revealing insights into their lives pre-diagnosis without probing trauma or relational disruptions. Similarly, Thompson *et al*<sup>25</sup> focused on the experiences of women diagnosed with non-epileptic seizures, identifying major themes related to living with the condition and its post-diagnosis impacts. Pick *et al*<sup>26</sup>

#### Figure 1.

Flow diagram of the literature search.

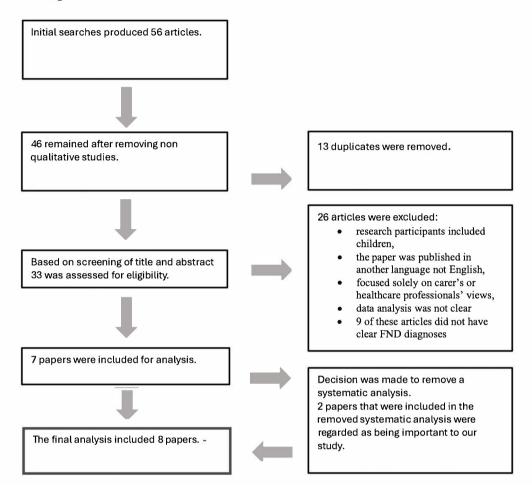


Figure 1 Flow diagram of the literature search. FND, functional neurological disorder.

explored the emotional responses to stimuli in patients with non-epileptic dissociative seizures, providing rich data on their lived experiences.

#### **Thematic analysis**

Three studies employed thematic analysis to understand the experiences of patients with various presentations of FND.<sup>28–30</sup> A London-based study used semistructured interviews to explore the narratives, illness experiences and psychological impacts of patients with functional motor disorder.<sup>28</sup> Rawlings *et al*<sup>30</sup> analysed written accounts from individuals with psychogenic non-epileptic seizures, identifying themes around living with the condition and emotional responses. In Montreal, Dickinson *et al*<sup>28</sup> used thematic content analysis on narratives collected via the McGill Illness Narrative Interview Schedule, uncovering themes related to life events and the onset of illness.

# Narrative typology method

Expanding on their previous work, Rawlings *et al*<sup> $p_1$ </sup> examined the narratives of patients with PNES or epilepsy, analysing their accounts through a narrative typology

seeking certainty in their conditions. tand ions ured Integrating the studies The material was organised and read immersively. Each

study had a different focus, so an integrative approach was adopted to synthesise the material. Two authors of the paper, both clinicians working with FND, adopted an immersive approach that took both line-by-line and topdown information into account to come to a synthesis of the material. A reflective discussion of possible themes ensued with eight themes emerging from this approach: lost, body–mind dualism, preceding stressful events, relatedness, stigma, the battle or fight, the burden and losses of the illness and trust versus mistrust. These themes were connected within the central overarching theme of relationally regulated selves, which posits the essence of the lived experience of FND as to do with the response to stressful experiences within a relational, regulatory

method. This approach revealed distinct narrative

patterns between the groups, with patients with epilepsy

focusing on managed adversity and patients with PNES

context. Both coders reflexively acknowledged and considered their experience in bodymind, FND, stress medicine and training in attachment.

#### **Relationally regulated selves**

Relationally regulated selves as the overarching theme encompasses the multiple systems involved in well-being including the relational aspects of regulation and their disruption.

The relational aspect of healing was the crucial outcome of Affray's thesis.<sup>27</sup>

If CD, because its cause is not yet known, means those with the diagnosis must be cared for rather than cured, then the form that care takes becomes the preeminent issue. (p 107)

This notion is similar to Winnicott's<sup>32</sup> 'holding environment', cocreated in therapy for the patient, to be able to facilitate the emergence of the true self or regulated relational self. Furthermore, Kain and Terrell<sup>33</sup> point out that therapy intends to build a support scaffold for the patient, hoping to increase capacity for self and coregulation.

## Lost

The theme of lost was prominent in all eight papers.<sup>24–31</sup> Being lost encapsulated the feelings of uncertainty that were fuelled by the lack of understanding of their condition and the lack of clear diagnoses and treatment plans; one described it as: '*being left in limbo land*'.<sup>25</sup>

One paper<sup>29</sup> explored experiences and perceptions of patients with functional motor disorder and found that some of the main themes reflected the experience of being lost, such as nobody knowing what was wrong, feeling abandoned and powerlessness. The sense is of being unmoored, without framework or adequate relational holding.

Patients often described health professionals and family members dismissing their symptoms, which added to the sense of being lost.<sup>25 31</sup> For example, in her phenomenological exploration of her own experience with conversion disorder, Affray<sup>27</sup> says poignantly, '*In many ways, this illness tests our ability to be with uncertainty.*'<sup>27</sup> A reoccurring statement, '*I feel lost*', is reported by Affray.<sup>27</sup> It is an attempt to describe how it is to live with a condition that alters one's sense of self via radical changes in the bodily experience.

In the study by Phoenix,<sup>24</sup> one participant describes the experience of his sense of self as lost: *It is just frustrating*. *You are two different people, and you are trapped in between them both.*' This entrapment is an important contributor to the sense of feeling and being lost.

# Preceding stressful events

Preceding stressful events were reported in five of the eight papers.<sup>25–28 30</sup> By stressful we mean events that cause the person to have difficulty managing allostatic load (by which we mean any mix of cognitive, emotional, interpersonal and physiological demands),<sup>34</sup> even though the

experience may be perceived negatively or positively or a mixture.

The events were wide ranging and included abusive childhood and adulthood experiences, divorce in the family, physical assault and non-specific adverse events.<sup>26</sup> Affray<sup>27</sup> writes about having influenza-like symptoms and working 16-hour days, 7 days/week, prior to the first FND event. Although likely a stressful period, Affray did not consider this an adverse experience.

In the study by Pick *et al*<sup>26</sup> responding to a specific question regarding the emotions/stress involved when seizures/attacks started and if the participants believe them to be related to their dissociative seizures:

I think ... when I was a child, I went through quite a bit of child abuse... and I think I locked that away, and I know because I just got on with it ... my way was to kind of get on with it ... I don't think on it at all, sometimes I'm kind of, not angry, I'll be upset that I had to suffer that, and now it's still affecting my adult life.<sup>26</sup>

#### Similarly:

I'd been attacked, shortly before that ... I was ok-ish then. I just went out for that walk ... got beaten up ... it all stemmed from there  $\dots^{26}$ 

16 out of 19 sufferers spontaneously reported past traumatic events. These included sexual, mental and physical abuse, loss, surgery, clinical depression and bullying in their school years.<sup>28</sup> Interestingly, the study by Hutchinson and Linden<sup>8</sup> revealed that patients emphasised the importance of triggering life events, a factor that clinicians often did not prioritise.

#### Mind-body dualism

Mind–body dualism as a strong theme was present in six papers.<sup>24–27 29 30</sup> This dualism becomes prominent when patients describe their disconnection from coherent self-experiences, a split between 'mental' and 'embodied' experience.

For example, in the paper exploring patients' difficulties with their emotions in dissociative seizures,<sup>26</sup> one participant states:

So it would seem like to have a seizure would take me out of my surrounding problems. ...Switched off, emotionally switched off, I don't feel anything ... I don't feel unhappy or I don't feel happy, I just feel as though somebody has literally switched me off and I'm not worried about anything.<sup>26</sup>

# Furthermore, Affray<sup>27</sup> writes:

My body wants to run away. My mind grasps at this and that. I feel like a glass, cracked, but still being used, until the smallest of taps ... and the glass is now a pile of shards on the counter, completely disintegrated.<sup>27</sup>

Similarly, in Phoenix's<sup>24</sup> thesis exploring the sense of agency of male participants diagnosed with FND, the

experience of the body being disconnected emerges. This is described by the participants as their body being experienced as a separate entity that they cannot control via their conscious mind. There is also an emphasis on the centrality of the conscious mind, a focus that further enhances the disconnection of their coherent self-experience or their regulated relational selves: '*It's really strange, your body's doing something you just can't control. It's very strange, very strange, because you're aware that it's happening, but you can't do anything about it.*<sup>24</sup>

The body–mind disconnection theme in this review may also reflect how treatment for patients with FND is often offered in a very incoherent and disconnected way.<sup>24 26 28</sup> As we know from a wide range of literature, patients are often sent to psychiatry only to be sent back to neurology<sup>6</sup> or vice versa. Often healthcare professionals lack education and knowledge of FND and so try to treat symptoms separately without the collaboration of a multidisciplinary team<sup>9 10</sup> or a conceptually integrated approach.

# **Relatedness**

The theme relatedness was strong in seven papers.<sup>24–30</sup> Relatedness was composed of the notions of being cared for, supported or at the opposite of that spectrum: being rejected and experiencing relational ruptures, such as shame and abandonment. In her thesis, Affray<sup>27</sup> discovers that finding a guide was essential for her healing:

I need a guide to help me through the inner. I have a deep sense that if I let go completely, and enter the inner alone, I could get 'lost' in there.<sup>27</sup>

I spoke with her today. It was soooooo good to be heard, held, and contained in her wisdom. Not alone trying to make my way. I have a teacher, a guide, a witness to my journey.<sup>19</sup>

Family, partners and friends were reported as the primary source of meaningful support.<sup>26</sup> <sup>28</sup> <sup>30</sup> As one participant states, '*I think I have gotten through my condition a lot faster and made a vast improvement due to my family and friend's support...*'<sup>30</sup> (p 86).

Clearly, the healthcare professionals who were relating with care, who listened and believed the patients, were valued as significant in their healing: 'He's taken more interest in me than anybody else has' and '[The neurologist] made me feel very different than anyone else had ... he is interested, and that felt really good.'<sup>25</sup>

On the opposite end of the spectrum, patients often felt abandoned, not believed in or even shamed by healthcare professionals:

So, I was always led to feel almost, ah, I don't want to, I don't know embarrassed but, quite shamed, in that that was the reason. That's how I always felt, in that I was contributing or a contributory to my condition. Um, without anyone actually coming out and saying that, that was kind of how I was always left to feel.<sup>29</sup>

Furthermore, some participants saw rupture in their close relationships as the leading cause for their symptoms emerging:

I can remember my first day, my first seizure started ... the problem I was facing at home had just got to a point where I just couldn't deal with it any more ... I got to my limit ... something had to give, and for me, it obviously manifested in a seizure.<sup>26</sup>

# **Stigma**

Patients feeling stigmatised were prominent in four papers.<sup>24</sup> <sup>27</sup> <sup>29</sup> <sup>30</sup> The layers and reasons of stigmatising experience were the stigma of the illness, the symptoms perceived as a mental disorder and the lack of education of the healthcare practitioner. For example, sufferers of PNES<sup>30</sup> report the following:

Not to mention the stigma of the disease. How people freak out and often yell at us when we have a seizure. Do you yell at people who have cancer or heart disease? What gives them the right to judge me.<sup>30</sup>

Similarly,<sup>24</sup> a participant recounts a distressing episode:

The neurologist, his answer was 'it's psychosomatic'. You actually go into a state where 'am I mad?' because the neurologists don't go further into this and actually explain. It breaks you into pieces. GP's, the same thing, they tell you, '...well, we don't know, we can't help you.' I actually ended up in in the hospital where I was in the psych ward and I met these doctors of mine and they just said, 'well, we need to find out what's wrong.'<sup>16</sup> (p 94)

At times patients turned stigma against themselves, judging that their symptoms were their bodies' sudden change of capabilities.<sup>30</sup> Stigma left patients feeling ostracised, marginalised and accused of feigning and being hypochondriacs.<sup>24 27 29 30</sup>

#### The battle or fight

The battle or fight theme covered anger, need for control, fighting the healthcare system and fighting patients' internal systems of understanding selves and the world and appeared in seven papers.<sup>24–31</sup>

Phoenix's thesis<sup>24</sup> presented many strong examples:

If someone out the blue asks me 'what's wrong', if like a stranger asks me, I say well 'a woman run me over with a car'; I'm not an angry person you know, but inside I get angry I think.<sup>24</sup>

I can't describe it, it was just, 'I'm really angry', but I couldn't show it because I couldn't speak.<sup>24</sup> (p 105)

Pick et  $al^{26}$  also offer a strong example, 'I had to toughen up, to be strong ... so I was a fighter, I fight for things that I want...<sup>26</sup>

Patients often had to fight the medical system to be heard and receive appropriate care:

At emergency they didn't do any treatment. They even wanted me sent home. But it was me that held my ground, I have something, I'm staying in the hospital. If you don't find anything, send me to neurology, send me anywhere, but I'm staying in the hospital. I had to fight.<sup>28</sup>

#### The burden and losses of the illness

The burden and losses due to the illness comprised the drain that living with FND and related disorders brought: the grief, isolation, loss of capacity and sense of self, loss of identity, and other kind of losses like financial, professional and so on, significant in six of the papers.<sup>24 25 27 29 30</sup>

Affray states, '*I am grieving the loss of my identity*.'<sup>27</sup> Likewise, in Rawlings *et al*, one participant says:

I don't feel like the husband and father I use to be. I am not able to do as many fun things as I use to do with my kids and it hurts them and me when I see them with that dejected look when I am so tired after a seizure that I can't move.<sup>30</sup>

The losses from the illness are also described<sup>29</sup>:

I have been off for the last 13 month ... It has drastically affected my life over the last 13–14 months. I have lost virtually a year of my life because of my condition.<sup>29</sup>

Thompson *et al*<sup>25</sup> also describe similar findings:

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.<sup>25</sup>

It's wrecked my life. I wanted to study, I wanted to be a nurse ... I've had to give everything up because of these stupid seizures ... It's all gone.<sup>25</sup>

# **Trust versus mistrust**

Trust versus mistrust encompasses the experience of being believed and understood, or not, and it explicitly arose as a significant experience in six papers.<sup>25–30</sup> Not being believed by the medical profession was a common occurrence and constituted a painful and intense experience for some. Being subjected to humiliation, questioning or suggesting that symptoms had been feigned and they need to get over it can be repeatedly found throughout the papers.<sup>27 30</sup>

Rawlings *et al*,<sup>30</sup> for example, report the following:

I am a nurse and worked on a neuroscience ward. We have Participant who's mum has pseudo seizures and the nurses always mock her or say she is weird and fakes seizures—these are professionals and even they don't understand it.<sup>30</sup>

Trust is a bidirectional phenomenon<sup>35</sup> developed in caring, supportive interaction between patients and medical professionals. As one participant's statement demonstrates: '*It was so pleasing that someone could sit and listen to my story, and ... say, 'oh I know exactly what that is*'.<sup>25</sup>

#### DISCUSSION

Our findings suggest a relative lack of in-depth, broadscope studies in the English language exploring the lived experience of the sufferer.

During our review process, we encountered a study by Dosanjh *et al*<sup>20</sup> that examined the period from symptom onset to diagnosis in functional movement disorder (FMD). Their research identified three themes reflecting stages in the patient journey, which resonated with our themes of body–mind dualism, relatedness and feeling lost. Furthermore, their findings echo the struggle for adaptation, highlighting the significant relational and self-conceptual impacts of FND on patients' lived experiences. These observations align with our overarching theme of relationally regulated selves, reinforcing the importance of understanding the patient's perspective and context in FND research and treatment.<sup>20</sup>

Most studies focused on the lived experience of patients after diagnosis of FND. While this is valuable, it would also be beneficial to improve our understanding of the origins and context of the disorder in terms of life story, relational history and significant stressors, including traumas and losses. This review suggests that some of those stresses, losses and traumas might include relational conflict in any arena, stresses of many kinds and difficulties in the treatment journey. This needs to be addressed in future research and practice.

Furthermore, trust versus mistrust as a theme has very important implications in terms of the therapeutic relationship, suggesting that attention needs to be given to nurturing and repairing a trusting therapeutic relationship in the evaluation and treatment of this disorder.

Burden and losses caused by the symptoms and the process of diagnosis and treatment, and the burden of stigma have clear implications around working towards destigmatising the illness and the appropriate support for patients, families and carers. A recent paper on the experience of stigma in FND populations supports our finding that stigma needs to be addressed to provide better service for the patients.<sup>13</sup>

On a positive note, the recent adoption of a more unified naming and diagnosing protocol,<sup>2 4 11</sup> which is slowly replacing the previous definitions, is affording medical professionals and the wider caregiving community a better opportunity to comprehend sufferers. This development might be showing some effect on illness perception, as the large online questionnaire study by Butler *et al*<sup>16</sup> showed that despite clinician's perceptions of patients with FND as opposing psychological models, results indicate that patients have a balanced view on neurological and psychiatric aspects of the disorder.

The central theme that emerged from this review is 'relationally regulated selves', highlighting the need for a holistic approach to understanding aetiology.<sup>411</sup> Notably, a recent study by Bazydlo and Eccles<sup>17</sup> examined the experiences of individuals with FMD, identifying three primary challenges they face: intrapersonal, interpersonal and systemic. These findings align with our review, underscoring the significance of relational aspects of regulation and the impact of their disruption. Disruption of self and relationships shows up as a theme in other chronic conditions like chronic pain.<sup>36</sup>

As Bègue *et al*<sup> $\beta$ 7</sup> state, applying the biopsychosocial conceptualisation, 'FND is the embodiment of a disorder that present physically (eg, resembling stroke, epileptic seizures), yet etiologically shares similarities with mental health disorders.' Developing aetiological and treatment models looking at the disorder and its symptoms arising from disruption to homeostasis from an integrative, relational and developmental neuroscience framework appears to be a way to move forward.<sup>38 39</sup> This sits within an overarching biopsychosocial spiritual-cultural framework<sup>40</sup> and the growing understanding of the importance of dissociation.<sup>41–43</sup> Furthermore, multidisciplinary pathways with a patient-centred approach are suggested for FND.<sup>14</sup>

Given our findings, it is likely that a more detailed understanding of this illness will result from conducting studies that include the life stories, relational history, and all significant stress, trauma and loss of sufferers within their scope, and paths to recovery, as well as focusing on those suffering from FND-like symptoms prior to them being diagnosed.

# **STRENGTHS AND LIMITATIONS**

A strength of the current study is that it adds to the extant systematic review of the lived experience of patients suffering non-epileptic seizures<sup>22</sup> by exploring overarching FND presentations.

A limitation of this review is that there are simply too few studies. More are needed. Additionally, studies that make up the body of this review are somewhat more fragmented than cohesive: there were many different disorders and names, and differing impetus behind and goals of enquiry for each of the studies, as well as divergent methods.

None of the papers offered details of the patient's attachment, stress, trauma or loss history, aspects that are likely highly relevant to further the biopsychosocial understanding of FND. Most of the other papers were concerned with the patients' interaction with healthcare and treatment providers or the meaning making of symptoms. A more holistic view is likely needed in future qualitative work.

A further limitation is the focus on research published in English with included studies ultimately deriving from the UK and Canada. The opportunity to increase transferability by looking at research from around the world and in different languages and cultures would be an important future step.

#### CONCLUSION

Despite some limitations, these studies are still highly informative. There was a surprising prevalence of the eight identified themes, and they give valuable insight into the lived experiences of those with FND.

Further research is essential to gain a broad and deep picture of early childhood experiences and later relationality as they pertain to relational dynamics, coping, attachment experiences, stresses, losses and traumas, and to explore life stories around the time of illness development. Indeed, it is hoped that investigating and understanding lived experience in this more holistic way may support the therapeutic alliance and the processes around assessment, formulation, diagnosis and multimodal management, including support, opening possibilities for cocreating recovery pathways.

FND research could provide opportunities for applying new neuroscience insights on emotions and the embodied, relational mind, further reducing the Cartesian divide.<sup>19 38 42</sup> As suggested by Bailey *et al*,<sup>19</sup> embracing its complexity may guide collaborative approaches that better meet the complex biopsychosocial needs of patients.

**Contributors** AS: conceptualisation, writing (original draft), writing (review and editing), data collection, data analysis, project management. AS (corresponding author) is responsible for the overall content (as guarantor). AK: writing (review and editing), data analysis, supervision. LM: conceptualisation, methodology, data analysis, writing (review and editing), supervision.

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#### **ORCID** iDs

Andrea Szasz http://orcid.org/0000-0001-6668-209X Loyola McLean http://orcid.org/0000-0002-6004-0093

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