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McLoughlin, Caoimhe; McWhirter, Laura; Pisegna, Katerina; Tijssen, Marina A.J.; Tak, Lineke M.; Carson, Alan; Stone, Jon

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Review

Stigma in functional neurological disorder (FND) – A systematic review



Caoimhe McLoughlin^{a,*}, Laura McWhirter^a, Katerina Piseigna^b, Marina A.J. Tijssen^c,
Lineke M. Tak^d, Alan Carson^a, Jon Stone^a

^a Centre for Clinical Brain Sciences, University of Edinburgh, Edinburgh, United Kingdom

^b Montreal, Quebec, Canada

^c UMCG Expertise Centre Movement Disorders Groningen, University of Groningen, Groningen, the Netherlands

^d Dimence Alkura, Specialist center Persistent Somatic Symptoms, Nico Bolkensteinlaan 65, 7416 SE Deventer, the Netherlands

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ABSTRACT

Objective: The purpose of this systematic review was to evaluate stigma and Functional Neurological Disorder (FND) regarding: 1) prevalence and associated factors, 2) the nature and context of stigma in FND, and 3) stigma-reduction interventions.

Methods: We searched four relevant databases from inception to December 2023, using search terms relevant to FND and stigma themes. We employed the method of synthesis by “aggregation and configuration” to synthesise and analyse the data into emergent themes.

Results: We found 127 studies, spanning 148 countries, involving 18,886 participants. Of these, 4889 were patients, 13,123 were healthcare professionals, and 526 were caregivers. Quantitatively, stigma has been mainly studied in patients with functional seizures, and was higher than patients with epilepsy in three studies. Stigma experienced by patients is associated with poorer quality of life and caregiver burden. We found 10 themes and 29 subthemes revealing stigma as a systemic process, with intrapersonal, interpersonal and structural aspects. Few studies examined the perspective of caregivers, the public or online community. We identified six anti-stigma interventions.

Conclusion: Stigma in FND is a layered process, and affects patient quality of life and provision of care. Stigma needs to be addressed from the top structures, at governmental level, so that appropriate care pathways can be created, giving patients with FND parity of esteem with other medical conditions.

1. Introduction

1.1. Background to functional neurological disorder

Functional Neurological Disorder (FND) is a common condition describing a spectrum of neurological symptoms such as weakness, sensory changes, seizures, gait disturbance, tremor and speech disturbance (Hallett et al., 2022). Several terms have been used to describe FND throughout time –some of which include conversion disorder, dissociative neurological symptom disorder, medically unexplained, psychogenic, non-organic, pseudoneurological and hysteria (Bratanov et al., 2022; Raynor & Baslet, 2021; World Health Organisation, 2024). More recent changes in terminology somewhat reflect a transition from outdated conceptual models of FND. The current Diagnostic Statistical Manual of Mental Disorders- 5th revision now calls it “Functional Neurological Symptom Disorder (Conversion Disorder)”, a change from

simply “Conversion Disorder” in DSM-IV (2013; American Psychiatric Association, 1994). DSM-5 now define FND as; one or more symptoms that affect body movement or senses, findings on examination provide evidence of incompatibility between the symptoms and other recognised neurologic disease, and symptoms cause significant distress or problems in social functioning, work or other areas (American Psychiatric Association, 2013).

There has been a significant evolution of the theories that shape our current understanding of FND over the last century. Sigmund Freud’s theories in relation to trauma and hysteria are well recognised in the literature, however the concept of trauma being relevant to such symptoms was present prior to Freud (Briquet, 1859; Gamgee, 1878). Freud elaborated on the concept of repression as the mechanistic link in the presentation of such symptoms and in 1894, he introduced the term “conversion”: “*In hysteria, the incompatible idea is rendered innocuous by its sum of excitation being transformed into something somatic. For this I*

* Corresponding author.

E-mail address: c.mcloughlin@ed.ac.uk (C. McLoughlin).

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should like to propose the name of conversion" (Freud, Strachey, Tyson, Strachey, & Freud, 1894, p. 49). Freud considered the "conversion" symptom to play a role in the evasion of conflictual experience, particularly around repression of sexually traumatic events. Pierre Janet, a contemporary of Freud's, outlined the role of trauma and dissociation in the presentation of similar symptoms (Janet, 1889). While there is evidence that adverse life events play a strong role in etiology of FND (Ludwig et al., 2018), and psychotherapy is helpful for FND (Gutkin, McLean, Brown, & Kanaan, 2020), an over focus on the conversion theory and purely psychological explanations may in fact have obscured and delayed other important facts – such that FND has a multitude of triggers (Stone et al., 2009) and can be treated with a range of interventions including physiotherapy (Goldstein et al., 2020a, 2020b; Nielsen et al., 2016).

More recent pathophysiological explanations of the mechanism of FND allow for the importance of psychological factors and experiences but also examine FND at a neural level. They include aberrations of predictive coding framework, overactivity of the limbic system, and dysfunction of brain networks (Hallett et al., 2022). In a "predictive processing" paradigm prior beliefs and experiences form predictive models about the world, which are continually modulated by "top down" beliefs and bottom up" sensory information. In FND, it is hypothesised that abnormal predictions about movement, impacted by abnormal self-directed attention, overwhelm sensory evidence – resulting in the generation of movements that occur without a normal sense of volitional control or agency (Edwards, Adams, Brown, Parees, & Friston, 2012; Hallett et al., 2022; Perez et al., 2021). These conceptual models may be supported further by functional and structural changes in the brains of people with FND, which have demonstrated evidence of increased connectivity between motor control and emotional processing areas as well as alterations in networks related to sense of agency (Bégué, Adams, Stone, & Perez, 2019; Perez et al., 2021).

In line with more recent developments in our understanding of FND, the newest version of the DSM (American Psychiatric Association, 2013) demoted the term "Conversion Disorder" in keeping with the updated view that the "conversion" of stress to physical symptoms is an overly narrow conceptualisation of FND. Despite these updates, the area of terminology in FND remains a source of confusion and inconsistency (Bratanov et al., 2022). Though they are considered outdated, terms like "pseudo" and "psychogenic" are still in use (Dastgheib, Nazeri, & Asadi-Pooya, 2020; Yogarajah et al., 2018). Terms such as "hysterical" or "pseudo" are inaccurate descriptors and have clearly negative connotations, likely reinforcing stereotypes about individuals with FND being labile, out of control or non-genuine. Further to that, the multitude of names that exist for FND is likely to add confusion during clinical communication, when undertaking research, or when patients/caregivers are seeking out information. Terms such as "pseudoseizures", "psychogenic seizures", and "hysteria" are more than just misleading, often interpreted as offensive (Stone et al., 2002) and, furthermore, linked with expectations of non-recovery from psychological treatment (Loewenberger, Cope, Poole, & Agrawal, 2020). Previous reviews of terminology have outlined how the term functional seems to fit the criteria of acceptance by patients and HCPs, compared with other popular terms (Asadi-Pooya, Brigo, Mildon, & Nicholson, 2020; Ding & Kanaan, 2017). A further recent review shows how "hysteria" and "psychogenic" have lost popularity over time and Functional Neurological Disorder is the most popular in the scientific literature (Bratanov et al., 2022).

FND symptoms are a common reason for referral to neurology clinic (Ahmad & Ahmad, 2016; Stone et al., 2010). Women are disproportionately affected with rates of about 70% versus 30% men (Goldstein et al., 2019; Lidstone, Costa-Parke, Robinson, Ercoli, & Stone, 2022). It is a condition that carries a high level of disability and distress (Carson et al., 2011). Despite FND being a relatively common and disabling condition, it is often misconstrued as a condition that is confusing and less deserving of care compared with other conditions (O'Keefe et al.,

2021; Vance et al., 2024). The path to diagnosis is often unnecessarily protracted and complicated (Crimlisk et al., 2000; Williams et al., 2022) with patients often waiting many years before the diagnosis is even made (Kerr et al., 2016). These delays result in significant costs for healthcare systems (Stephen, Fung, Lungu, & Espay, 2021), as well as being prognostically damaging for patients (Gelauff, Stone, Edwards, & Carson, 2014).

1.2. Stigma and healthcare

There have been many developments in stigma theory and concepts since the seminal work by sociologist Erving Goffman (1963). He described stigma as the "situation of the individual who is disqualified from full social acceptance" (Goffman, 1963 preface); "he is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, pg. 3). Goffman had a particular focus on social interactions, and the role of the outside societal structures such as gender, ethnicity or class did not occupy much attention. (Scambler, 2009; Scambler & Paoli, 2008). In their later, influential, conceptualization of stigma, Link and Goffman incorporate the importance of power in their description of stigma as the co-occurrence of four processes: (1) labelling human differences; (2) stereotyping such differences; (3) separating those labelled from "us"; and (4) status loss and discrimination (Link & Phelan, 2001).

There was a subsequent shift in the literature beyond what occurs at the micro-level interaction, to broader societal aspects to the stigma process (Scambler & Paoli, 2008; Weiss, Ramakrishna, & Somma, 2006). Weiss et al. (2006) outlined how stigma occurs as a social process that can be characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgement about a person or a group. Scambler and Paoli (2008) put forward a re-framing of stigma concepts beyond earlier models, describing "enacted stigma" as "discrimination by others on the grounds of 'being imperfect'" and "felt stigma" as "internalized sense of shame and immobilizing anticipation of enacted stigma". Hatzembuehler (2016) discusses the importance of more macro-level components to stigma processes – that is the influence of societal and cultural norms and institutional policies. He describes how structural stigma impacts on individual stigma experiences – for example individuals with mental illness living in countries with low levels of structural stigma report lower self-stigma and perceived discrimination than countries with higher structural stigma (Evans-Lacko, Brohan, Mojtabai, & Thornicroft, 2011).

Stigma is influenced by the prevailing cultural norms; as Murthy describes, "stigma is universal but experiences are local" (Murthy, 2002). Within a certain social sphere, behaviours and attitudes (including towards the self), are likely to be impacted by shared cultural perceptions. Yang et al. (2007) proposed expanding the cultural conceptual lens of stigma to incorporate the concept of "moral experience", or "what is most at stake for actors in a local social world". It has been described how certain symptoms may carry a high sense of moral shame or stigma depending on the local cultural context. For example, certain Asian cultures and Latin American cultures perceive any mental health difficulties as a sign of an intrinsic deficit (Mascayano et al., 2016; Zhang et al., 2019). Certain African regions may view and appraise neurological and psychiatric symptoms through a supernatural lens, such as a result of spirits or curses (Braga et al., 2020; Ventevogel, Jordans, Reis, & de Jong, 2013), and certain Arabic regions may perceive similar symptoms to be as a result of religious punishment (Al-Dossari et al., 2018; Zolezzi, Alamri, Shaar, & Rainkie, 2018). Western cultures perceive individuals with such symptoms as dangerous or unpredictable (Corrigan & Watson, 2007). Similar cultural influences have been shown to affect local perceptions of FND, with a subsequent impact on help-seeking and treatment, as evidenced by studies based in Argentina, (María Marta et al., 2023; Sarudiansky et al., 2017) and India (Lakhani, Sharma, & Desai, 2022; Moyon, Thomas, & Girimaji, 2021).

While stigma is considered complex, and "a system of interrelated, heterogeneous parts" (Pescosolido & Martin, 2015), certain key aspects

have remained important in the evolution of the stigma literature. Stigma remains widely conceptualised to be experienced and perpetuated via prejudice, stereotyping and discrimination (Corrigan & Rao, 2012; Fox, Earnshaw, Taverna, & Vogt, 2018; Pescosolido & Martin, 2015; Thornicroft et al., 2016). Prejudice involves the emotional responses towards the group or individual such as pity or anger (Fox, Earnshaw, et al., 2018) and stereotypes are the way in which humans categorize information about groups of people (Corrigan & Rao, 2012). Discrimination is described as behaviours that act to endorse and reinforce stereotypes, and disadvantage those labelled (Pescosolido & Martin, 2015). Discrimination can be interpersonal or institutionalised and may involve practices or policies that either intentionally or unintentionally discriminate against people due to their differences, for example, being fired from job due to illness or being denied continuity of care.

From the perspective of the person experiencing stigmatisation, stigma has often been observed to occur in the following ways: experienced (felt and enacted stigma), anticipated, and internalised/self-stigma (Corrigan & Rao, 2012; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Fox, Earnshaw, et al., 2018; Quinn & Earnshaw, 2013; Scambler & Hopkins, 1986). Experienced stigma can be perceived/"felt" or enacted. "Felt" stigma refers to the extent of an individual's subjective experience of discrimination or prejudice, whereas enacted stigma is the experience of being discriminated against by others (Scambler & Hopkins, 1986). Anticipated stigma is the extent to which people expect to experience stereotyping, prejudice, and discrimination directed at them from others in the future, and internalised (self) stigma is the extent to which people endorse negative beliefs and feelings associated with the stigmatized attribute and apply them to the self (Corrigan & Rao, 2012; Earnshaw et al., 2013; Fox, Earnshaw, et al., 2018; Quinn & Earnshaw, 2013).

Stigma impacts on mood, health-seeking behavior and engagement with treatment across a range of conditions, and the need for addressing this has been clearly outlined (Fox, Earnshaw, et al., 2018; Fox, Smith, & Vogt, 2018; Quinn & Earnshaw, 2013; Stangl et al., 2019; Yan, Luo, Qiu, Ji, & Chen, 2020a, 2020b). From the perspective of the person experiencing stigmatisation, stigma will fuel treatment delays and psychosocial disadvantages, and leads to collective social rejection of the patient – this in turn influences policy formation and healthcare planning (Fox, Earnshaw, et al., 2018; Fox, Smith, & Vogt, 2018; Hatzenbuehler, 2016). In this way, stigma can be viewed as a systemic, interactional and cyclical process with long-lasting rippling effects.

1.3. Stigma and FND – what is known already

An online survey of almost 500 participants run by the FND charity FNDHope, showed that 85% of patients felt dismissed and disrespected on account of their FND (fndhope.org). HCPs have described patients with FND in negative terms (Ahern et al., 2009; Lehn, Bullock-Saxton, Newcombe, Carson, & Stone, 2019), and many clinicians consider patients have voluntary control over their symptoms, or perceive patients to be feigning (Dent, Stanton, & Kanaan, 2020; Lehn et al., 2019).

A recent review of stigma in functional seizures has been carried out by Annandale, Vilyte, and Pretorius (2022), showing themes of healthcare provider stigma, family and social stigma, role of the naming of the condition, impact of stigma on individuals' lives, and role of context and culture among other findings. This valuable review, while helpfully mapping out the nature, type and breadth of the literature on this topic, is scoping in nature – therefore the more detailed and nuanced areas of stigma, such as shame or institutional aspects were not explored in detail. In addition, this review only explored stigma in functional seizures. FND presents with a wide range of symptoms, and while functional seizures are a common presentation, so too are tremor and gait disorders (Hallett et al., 2022), where individuals also experience stigma (Bazydlo & Eccles, 2022). Furthermore, several important studies from a wide range of countries have been published since this review by

Annandale et al. (2022) that are relevant; including those from the patient perspective (Bazydlo & Eccles, 2022; Lakhani et al., 2022; María Marta et al., 2023; Peacock et al., 2023; Staton, Dawson, Merdian, Tickle, & Walker, 2023; Zeun & Hunter, 2023); from a HCP perspective (Alamrawy et al., 2023; Al-Sibahee, Hashim, Al-Badri, & Al-Fatlawi, 2023; Asadi-Pooya et al., 2023; Begley et al., 2023; Saker, Katson, Herskovitz, & Herskovitz, 2022; Yu et al., 2023), and the perspective of the general public (Coe, Nic Craith, McQuaid, D'Alton, & O'Connor, 2023).

Rawlings and Reuber (2016), carried out a narrative systematic synthesis of qualitative studies investigating patients' accounts of living with functional seizures, revealing themes related to stigma such as negative experiences with HCPs, patients feeling ignored, and patients seeking validation of their experiences. Foley, Kirkby, and Eccles (2022) carried out a synthesis of qualitative studies related to individuals with FND with more targeted exploration of their stigma experiences. This revealed the following themes; stigmatized by delegitimization; stigmatized by social exclusion and rejection; coping with stigma; and stigma and identity. Further relevant studies have been performed since these reviews, such as those by Lakhani et al., 2022; María Marta et al., 2023; Peacock et al., 2023; Staton et al., 2023; and Zeun & Hunter, 2023. These more recent studies build on the current existing literature (Foley et al., 2022; Rawlings & Reuber, 2016), and incorporating these additional studies into the present study shed further light onto how stigma is experienced from the perspective of the individual, across different global regions.

Rawlings and Reuber (2018) reviewed the literature on healthcare perceptions of functional seizures, revealing themes of: uncertainty around diagnosis and treatment of functional seizures; dualistic and narrow understanding by HCPs; HCPs held negative views of patients; HCPs held mixed views about who is responsible for treating this group; and this condition was viewed as less severe/disabling than epilepsy. This review only includes HCP perceptions of functional seizures, though evidence of stigmatizing attitudes exists towards patients with other functional neurological symptoms outside seizures (Bazydlo & Eccles, 2022; Begley et al., 2023). Additionally, further studies have been carried out since this review was undertaken from the perspective of HCPs, from diverse regions, which have been integrated into the present study (Alamrawy et al., 2023; Asadi-Pooya et al., 2023; Barnett et al., 2021; Begley et al., 2023; Fouché, Hartwig, & Pretorius, 2019; Hutchinson & Linden, 2021; Jordan, Feehan, Perdue, Murray, & Goldstein, 2019; Lehn et al., 2019; Marotta et al., 2023; O'Connor & Reuber, 2021; Nicholson, Francis, Nielsen, & Lorencatto, 2021; Saker et al., 2023; Taplinger, Manning, & Henninger, 2020; Terry & Trott, 2019; Yu et al., 2023; Xie et al., 2021).

While the interpersonal impacts of stigma on the individual with FND and their wellbeing have been described (Foley et al., 2022; Rawlings & Reuber, 2016; 2017a, 2018b; Robson, Myers, Pretorius, Lian, & Reuber, 2018), it is likely there are more far-reaching implications of stigma in FND, particularly around service development, healthcare utilisation, healthcare costs and education/training. A survey of professionals from 63 countries revealed that "stigma/lack of awareness" was the main barrier to the diagnosis and treatment for functional seizures in 70% of countries (Hingray et al., 2017); and low availability of services to refer to was one of the factors considered as 'often' or 'always' limiting patient management in 48% of clinicians in another international study spanning 92 countries (LaFaver et al., 2020).

Individuals with FND are likely to wait a long time to be seen by a specialist who can either diagnose them or provide clinical services (Asadi-Pooya & Tinker, 2017; Bahrami, Homayoun, & Asadi-Pooya, 2019; Bodde et al., 2012; Kerr et al., 2016, 2021), which is likely to be in some part due to a lack of interest in clinicians and policy makers around FND. Compared with other neurological conditions, the wait time for a diagnosis of FND has been shown to be particularly long (Cuoco et al., 2023; O'Keefe et al., 2021). This has direct implications on healthcare utilisation costs, as outlined in a recent publication by

Williams et al. (2022). They describe how patients assessed for likely FND in the emergency department (ED) followed circular pathways which “looped around ED”. In addition to being unsatisfactory for individuals with FND, these circular pathways also strain resources. The patients in this study had low rates of documented diagnosis and low rates of referral for psychological therapy, however the authors found that when the FND diagnosis was documented and referral to clinical psychology and outpatient neurology occurred, ED attendances for this group reduced, with associated healthcare savings. A further recent study found that diagnostic delay was much longer for patients with FND compared with other neurological disorders, with diagnostic delay correlating significantly more strongly with increased costs in patients with FND (Cuoco et al., 2023).

Further structural implications of stigma in FND include a lack of prioritisation in teaching curricula. Recent studies from Iraq, USA and France have outlined the how training in FND is lacking and suboptimal (Al-Sibahee et al., 2023; de Liège et al., 2022; Milligan et al., 2022). Professionals and academics have unfortunately perpetuated stigma through not prioritising FND in undergraduate and postgraduate training, and during certain periods FND is barely to be found in the medical teaching curriculum at all (Stone, Hewett, Carson, Warlow, & Sharpe, 2008). More junior staff who may be well-meaning are then exposed to these negative attitudes– the so-called ‘hidden curriculum’ (Hafferty, 2015) and so, the systemic cycle continues.

Stigma in FND also occurs in the public domain (Carruthers, Fernandes, Agrawal, & Poole, 2021; Coey et al., 2023)– including online (Myers, Jones, Boesten, & Lancman, 2016). These aspects are not visible in the aforementioned existing literature, and such perspectives are important to incorporate, given how both the experience and perpetuation of stigma is likely influenced by wider public perceptions. Lastly, while there is some literature available on protective factors against stigma in FND (Annandale et al., 2022), there is limited literature describing targeted anti-stigma interventions for FND.

The topic of stigma in FND and need to address it has been highlighted by others (MacDuffie et al., 2020; Rommelfanger et al., 2017). Given the potentially negative consequences of stigma experiences for patients for FND, there is a need to deepen our understanding of how and when it occurs, so interventions can be developed to alleviate it. To our knowledge there is limited evidence integrating all these different viewpoints of stigma in FND from the perspective of patients, HCPs and healthcare systems, family/caregivers, media and society, which is the aim of the present study.

2. Present study

This aims to evaluate the existing evidence with regard to stigma and FND. Specifically, the following questions will be addressed:

1. Has stigma in FND been quantitatively measured – what are the prevalence and associated factors?
2. Where and how does stigma present in FND, for patients, HCPs and caregivers, on an interpersonal and systemic level, considering the components of relevant stigma frameworks?
3. Which interventions help to reduce stigma in FND?

The current study is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe) ultimately aiming to improve the understanding of mechanisms, diagnosis, treatment and stigmatisation of Functional Disorders (Rosmalen et al., 2021). This review was pre-registered on Open Science Foundation (registration number [OSF.IO/QS4H6](https://osf.io/QS4H6)).

3. Methodology

We searched the databases Medline, PsycInfo, Embase, and the Web of Science database from inception to 2nd December 2023. The

systematic review was carried out in a stepwise fashion in accordance with PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidelines (Page et al., 2021). We consulted the ENTREQ guidelines given the considerable amount of qualitative data relevant to our review (Tong, Flemming, McInnes, Oliver, & Craig, 2012). We used a range of subject headings and free text terms that have been applied to FND. These terms were combined with the AND operator with the free text and subject headings used to cover stigma themes. See appendix A, supplementary material for description of search terms. In addition to these databases, the reference lists of selected papers were checked for relevance.

3.1. Inclusion and exclusion criteria

We included cross-sectional or longitudinal studies, using quantitative, qualitative, and mixed methods designs. The study must have reported on a topic encompassing stigma and FND – including self-stigma, discrimination, labelling, prejudice, stereotyping, or any example where the patient was clearly being treated differently than standardized practice, or not being fully socially accepted due to having a diagnosis of FND. Our investigation was guided by the current literature on stigma frameworks in healthcare, taking into account intrapersonal, interpersonal and systemic aspects. Studies that focussed on reducing stigma in some form (for example challenging negative attitudes, changing perceptions and encouraging patient empowerment), were included. We did not include studies that focussed primarily on professional education or psychological treatment, such as cognitive behavioural therapy-informed psychoeducation. Studies were also included if they reported these same themes affecting professionals and caregivers associated with a patient with FND, or reported perspectives of the general public. We did not include discussion papers, conference papers or reviews. We excluded articles that were not written in English, non-peer reviewed literature, or ones that did not focus primarily on FND or stigma-related themes.

3.2. Identification of papers and bias reduction

Based on title and abstract screening, two of the authors (CM, LM) independently selected studies for full-text screening. Studies were not included if they did not fit the inclusion criteria. We resolved any disagreements about final full text inclusion through discussion between the study authors. We identified a total of 7345 articles from the databases searched; 803 duplicates were removed leaving 6542 articles. The title and abstract of these papers were checked for relevance by CM and LM and following this 6071 were removed. We sought 471 for retrieval and assessed 470 articles for eligibility (one not able to be retrieved despite contacting the author). At this stage, 354 were excluded as they did not meet the inclusion criteria following full-text review. At this point 116 studies remained for inclusion for review for data extraction. A further 11 were added from checking the reference lists of included studies, resulting in 127 for final inclusion. See Fig. 1 PRISMA flowchart.

3.3. Grouping and analysis

This was a mixed method systematic review. Given that stigma traverses many aspects of healthcare – from the clinical interaction to more complex policy decisions, we considered this type of methodology to be more informative and complete than undertaking a single-method review (Stern et al., 2020). We grouped the studies according to methodology and whether they focused on the perspective of the patient, HCP, caregiver or the general public. Regarding quality assessment, we used the Mixed Methods Assessment Tool (MMAT)– a critical appraisal tool designed for appraisal of qualitative, quantitative and mixed methods studies (Hong et al., 2018; Hong, Gonzalez-Reyes, & Pluye, 2018). This tool consists of two screening questions, and then five questions relevant to the study’s methodology, with scores ranging from

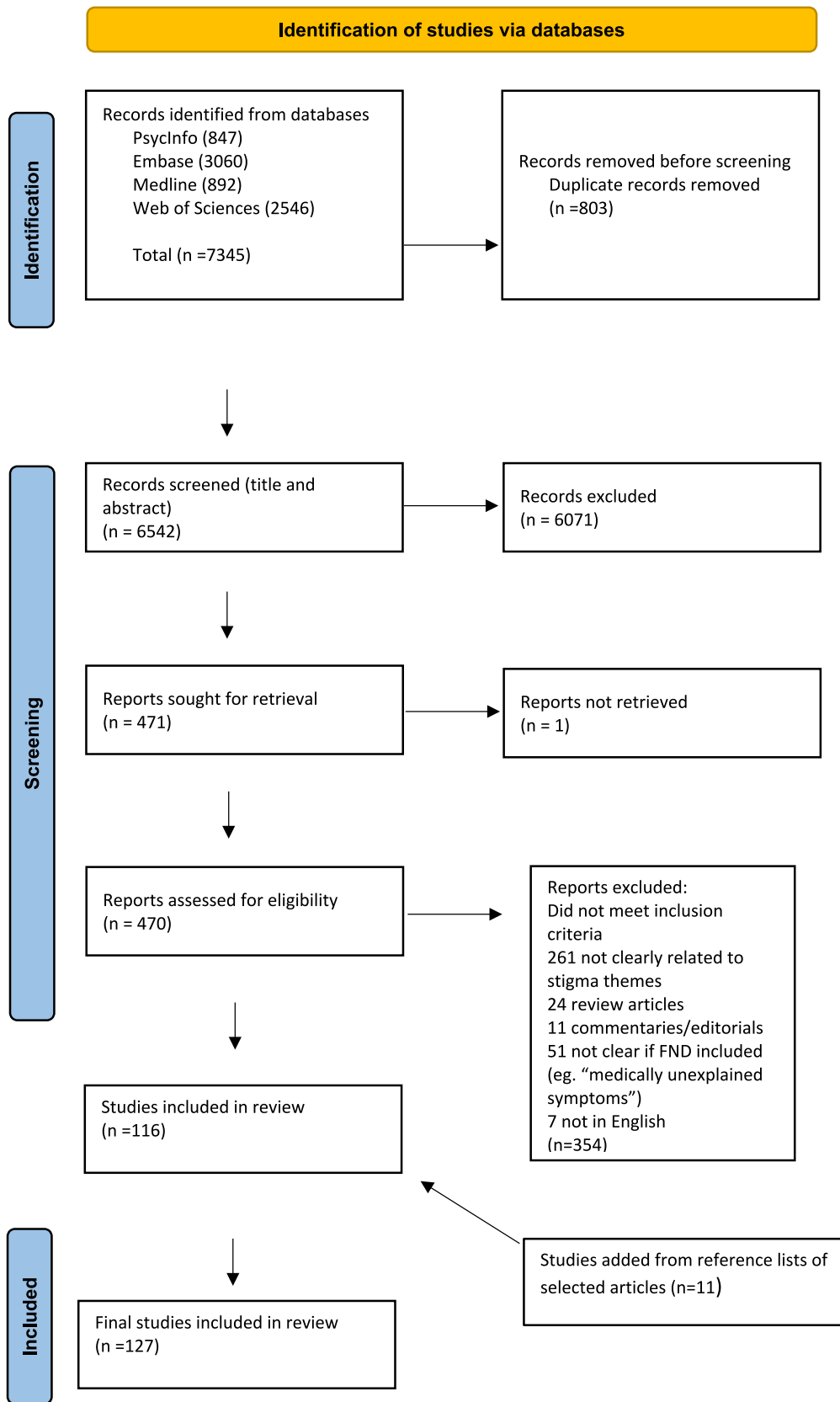


Fig. 1. PRISMA flowchart of study selection.

one star * to five*****. We did not perform a meta-analysis of the data due to the high heterogeneity in the study populations, methodologies, and outcome measures of included studies.

The optimal way to analyse and synthesise mixed method studies remains an area of debate. It has been noted that primary studies that vary in methodology may yield thematically similar findings, and so a binary approach to analysing qualitative and quantitative research is best avoided (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Sandelowski, Voils, Leeman, & Crandell, 2011). Stern et al. (2020) draws on much of the previous evidence on this topic, collating an updated methodological approach for conducting a mixed methods systematic review, with a focus on data synthesis and integration of the evidence.

Since the present review focuses on different dimensions of stigma in FND, we followed different approaches when it came to 1) gathering and 2) synthesising the data for each question. Regarding question 1 (prevalence of stigma and associated factors), this could only be answered by examining quantitative papers. Regarding questions 2 and 3, these involved examining both quantitative, qualitative and mixed methods studies (Stern et al., 2020, Fig. 3).

With regards to synthesis and presentation of results, for question 1, our data were not amenable to meta-analysis or alternative statistical synthesis methods due to limited evidence and heterogeneity. We therefore used a structured summary with detailed presentation of all the relevant results for this question to ensure transparency. This type of structured narrative summary and presentation is outlined in the most recent PRISMA guidelines and related evidence for this type of data (McKenzie & Brennan, 2019; Page et al., 2021). For questions 2 and 3, since this part of our review focussed on different dimensions of the phenomenon of stigma, we followed a *convergent segregated approach* to its synthesis and integration (Stern et al., 2020).

This approach involved extracting data from the qualitative, quantitative and mixed methods studies and transforming the data into a mutually compatible format. We followed recommendations from the Johanna Briggs Institute (Lizarondo et al., 2019; Stern et al., 2020), for this method, such that quantitative data should be “*qualitized*” – or converted into themes/narratives. This involved extracting data from the relevant quantitative studies and converting it into textual descriptions to allow its’ integration with the data from the qualitative studies. This process involved a narrative interpretation of the quantitative results. In terms of our decision around data extraction for the quantitative studies, we extracted data that were relevant to our research questions on stigma in FND - for example attitudes, perceptions, or barriers to services. We grouped the quantitative studies into HCP, patient, mixed HCP/patient, or general public. Given the high heterogeneity, we carried out a narrative textual description of the relevant results. We then assembled and pooled these textual descriptions (qualitized data) with the qualitative data extracted from qualitative studies.

With regards to synthesis of the qualitative data, we employed the method of meta-aggregation, where we avoided re-interpretation of included studies, but instead aimed to present what the initial authors found (Lockwood, Munn, & Porritt, 2015). The themes of the results sections of the papers were considered, including the participant quotes verbatim, and authors’ interpretations of them. These were found through repeated reading of resulting themes and associated quotes relevant to stigma – for example, if a study described general patient experiences of functional seizures, we only extracted data clearly relevant to stigma, such as aspects of self-stigma or HCP prejudice. CM undertook repeated, detailed examination of this assembled data, identifying and forming categories that were related in meaning/concept – for example HCP dismissal, shame, or status loss. CM and JS held consensus meetings regarding the category descriptions and final synthesised findings. We then undertook examination of this assembled qualitative and qualitized data to identify categories on the basis of similarities in their meaning overall (similar to meta-aggregation)

above.

Following thorough and repeated review of all included studies, we interpreted which factors were continually identified as influential to our research questions, integrating recognised stigma frameworks and concepts (Corrigan & Rao, 2012; Earnshaw et al., 2013; Fox, Earnshaw, et al., 2018; Pescosolido & Martin, 2015; Quinn & Earnshaw, 2013; Scambler & Hopkins, 1986; Thornicroft et al., 2016), to inform our findings – such that the underlying concepts and theory drove our construction of the themes, and merged the findings into a pooled summary of the main themes. We then explored the potential links between these findings and arranged the sets of aggregated findings into a coherent narrative, to produce the overall integrated findings of this review (Sandelowski et al., 2011; Stern et al., 2020).

4. Results

4.1. General characteristics

These final studies selected for inclusion in this review spanned 148 different countries – the majority from the UK (55), followed by US (31). See Fig. 2.

Regarding quality appraisal, the overall result of the quality appraisal was very mixed. A strength of included studies were many included patient quotes, which were helpful in describing the subjective experiences of stigma. We aimed to prioritise stronger papers that answered our research question and ensured no themes relied only on weaker papers.

There were several different methods of data collection used (for example, structured questionnaires, online surveys and semi-structured interviews, among others). Sample sizes ranged between five (Peacock et al., 2023; Sarudiansky et al., 2017) and 1146 study participants (Hingray et al., 2017), representing 18,886 in total.

Of these, 4889 were patients; of these patients, 3751 were diagnosed with FND, 750 were being worked up/investigated for FND, and 388 were diagnosed with other neurological disorders. Of the other participants, 13,123 were HCPs and 526 were caregivers (367 caregivers of patients with FND and 159 caregivers for patients with other neurological disorders). Finally, 348 participants did not have a medical diagnosis or were volunteers.

Out of 127 studies, 57 studies reported stigma themes from the perspective of the patient, 10 of which included a caregiver perspective (Cope, Smith, Edwards, Holt, & Agrawal, 2021; de Gusmão et al., 2014; Gurcan et al., 2022; Karakis et al., 2020; Karakis et al., 2020; McWilliams, Reilly, McFarlane, Booker, & Heyman, 2016; Pohlmann-Eden, Eden, & Smith, 2019; Robson & Lian, 2016; Teagarden et al., 2020; Whitehead, Stone, Norman, Sharpe, & Reuber, 2015). In total 59 studies reported on stigma themes from the HCP perspective. These were mainly neurologists and psychiatrists, but also included many other HCPs – nursing, occupational therapy, physiotherapy, psychology, speech and language therapy, general practitioners (GPs) and emergency and internal medical staff, among others. Six studies looked at stigma themes from the perspective of HCPs and patients (Carton, Thompson, & Duncan, 2003; Hall-Patch et al., 2010; Herbert, Kim, Hassan, Wilkinson-Smith, & Waugh, 2021; Hutchinson & Linden, 2021; Robson & Lian, 2016; Whitehead, Kandler, & Reuber, 2013). Five studies focused on public perceptions; one an analysis of media portrayal of neurological disorders (Popkirov et al., 2019), one examined the views of FND espoused by media, medical, and patient groups (Carruthers et al., 2021), one an evaluation of terminology (Loewenberger et al., 2020), one evaluating representation of functional seizures in the online domain (Myers et al., 2016), and one compared general public responses to biomedical versus biopsychosocial framings of functional seizures (Coey et al., 2023).

Concerning type of FND, 87 studies focussed on functional seizures, 31 on FND as a whole, 10 focussed on functional motor symptoms (Bazydło & Eccles, 2022; Crimlisk et al., 2000; Dosanjh, Alty, Martin,

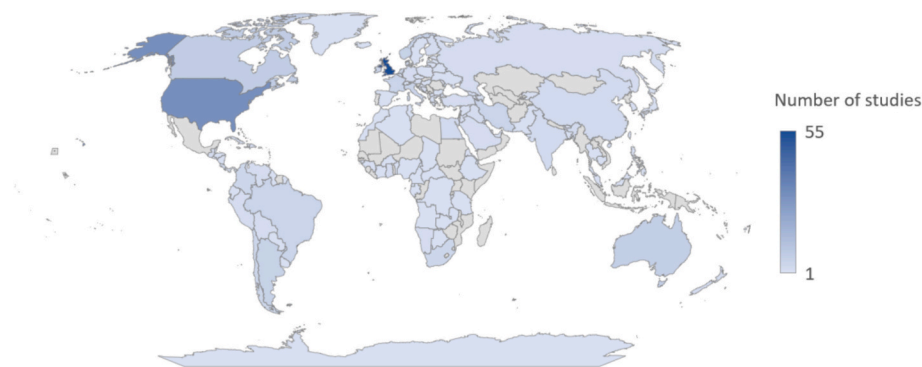


Fig. 2. Distribution of studies across countries.

Latchford, & Graham, 2020; Edwards, Stone, & Nielsen, 2012; Espay et al., 2009; LaFaver et al., 2020; Nielsen, Buszewicz, Edwards, & Stevenson, 2019; Tinazzi, Gandolfi, Landi, & Leardini, 2021; Xie et al., 2021; Zeun & Hunter, 2023); and one on functional speech and language symptoms (Barnett, Mitchell, & Tyson, 2022). Twelve studies focussed on children and young people (de Gusmão et al., 2014; Gurcan et al., 2022; Herbert et al., 2021; Karterud, Risør, & Haavet, 2015; Karterud, Haavet and Risør, 2016; McWilliams et al., 2016, McWilliams, Reilly, & Heyman, 2017; Moyon et al., 2021; Say, Tasdemir, Akbas, Yüce, & Karabekiroglu, 2014; Tanner, von Gaudecker, Buelow, Oruche, & Miller, 2022; Terry & Trott, 2019; Valente, Alessi, Vincentiis, Santos and Rzezak, 2017a). We found six studies that had anti-stigma interventions as the focus - these were mainly educational interventions (Cope et al., 2021; Gurcan et al., 2022; Hall-Patch et al., 2010; Medina et al., 2021; Pohlmann-Eden et al., 2019; Thompson, Osorio, & Hunter, 2005). See Appendix B, supplementary material for a table of included studies. For consistency throughout our review, we replaced the terms non-epileptic seizures (NES), functional non-epileptic attacks (FNEA), non-epileptic attack disorder (NEAD) and psychogenic non-epileptic seizures (PNES) with functional seizures.

Question 1: Has the stigma in FND been quantitatively measured – what are the prevalence and associated factors?

4.2. Prevalence of stigma in patients in FND

We found four studies that used a known stigma-specific measure (Karakis, Janocko, et al., 2020; Karakis, Morton, et al., 2020; Robson et al., 2018; Teagarden et al., 2020). The Jacoby 3-item stigma scale (also known as the Liverpool Stigma Scale) was used in three of these studies (Karakis, Janocko, et al., 2020; Karakis, Morton, et al., 2020; Teagarden et al., 2020), which assessed the same population of patients. Robson et al. (2018) used the 10-item Epilepsy Stigma Scale. A further fifth study examined perceived stigma using one question taken from the Quality of Life in Newly Diagnosed Epilepsy Instrument-6 dimensions (NEWQOL-6D), using a question originally derived from the Stigma of Epilepsy Scale (Rawlings, Brown, & Reuber, 2017). These studies assessed stigma in patients with functional seizures; and two used a control group of patients with epilepsy (Karakis, Janocko, et al., 2020; Rawlings, Brown, & Reuber, 2017).

In (Karakis, Janocko, et al., 2020), 76.5% of patients with functional seizures and 59.5% of patients with epilepsy reported feeling stigmatized, and 72% of caregivers of patients with functional seizures versus 47% of caregivers of patients with epilepsy felt stigmatized. In the Liverpool (Jacoby) scale, scores range from 0 to 3, where a score of 0 indicates that the person does not feel stigmatized, and a score from 1 to 3 indicates the person does feel stigmatized; the higher the score, the greater the person's perception of stigma (Baker, Brooks, Buck, & Jacoby, 2000). Mean stigma scores were higher in patients with functional seizures than epilepsy (mean: 1.7 versus 1.2) and higher in caregivers of patients with functional seizures than caregivers of

patients with epilepsy (mean: 1.3 versus 0.8) (Karakis, Janocko, et al., 2020). In Rawlings, Brown, and Reuber (2017), the risk of experiencing perceived stigma in functional seizures was 42% higher than the risk in epilepsy, assessed with a question taken from the NEWQOL-6D. We can infer from these studies that stigmatisation experienced by patients with FND is around 40% more likely than stigmatisation experienced by patients with epilepsy.

Out of the remaining three out of five studies, two assessed stigma in the same population of patients with functional seizures and their caregivers, showing that stigma perception was evident for both patients and caregivers using the Jacoby (Liverpool) scale); patient stigma mean score 1.7; and caregiver stigma mean score 1.3 (Karakis, Janocko, et al., 2020; Teagarden et al., 2020). Robson et al. (2018) assessed stigma using the 10 item Stigma Epilepsy Scale, where overall median scores (1–7) were calculated, finding the median stigma score across the whole group of participants was 5.2, indicating high levels of perceived stigma.

4.3. Factors associated with stigma

4.3.1. Quality of life

Karakis, Janocko, et al. (2020) compared patients with functional seizures and patients with epilepsy, finding that for the patients with functional seizures, overall Quality of Life (QoL) score correlated with stigma experienced by patients, with lower QoL scores predicting higher patient stigma. Robson et al. (2018) found a significant inverse correlation between perceived stigma and health related quality of life (HRQoL) in patients with functional seizures measured on the QOLIE-31 total scores, suggesting higher perceptions of stigma contribute to poorer HRQoL in patients with functional seizures.

4.3.2. Perception of self-control

Rawlings, Brown, and Reuber (2017) examined patients with epilepsy and patients with functional seizures – finding that in both conditions, perception of self-control was negatively associated with stigma - those who reported having a greater sense of control over events happening to them were less likely to perceive stigma.

4.3.3. Caregivers

For the caregivers of patients with functional seizures, lower patient overall QoL score, higher level of patient and caregiver anxiety predicted higher caregiver stigma level (Karakis, Janocko, et al., 2020). In a study of caregiver burden as measured by the Zarit Caregiver Burden Inventory (ZCBI), there was a significant positive association between caregiver burden and stigma experienced by caregivers of patients with functional seizures (Karakis, Morton, et al., 2020).

Question 2. Where and how does stigma present in FND, for patients, HCPs and caregiver, considering the components of relevant stigma frameworks?

Our data analysis revealed 10 main themes and 29 subthemes (nine main themes and 27 subthemes related to stigma, and one main theme

with two sub-themes related to anti-stigma). These are summarised with illustrative quotes in Table 1.

4.3.3.1. *Theme 1. Social exclusion.* Social exclusion manifested as a significant theme – which links to anticipated stigma and discrimination. The following subthemes arose: a) social isolation, b) employment and driving restrictions and c) socioeconomic status.

4.3.3.2. *Subtheme 1a: Socialization.* She spent a year in the bedroom and the school just gave up and we brought someone who would come in every now and again. But nevertheless for a year she lost her social skills and she's never really caught up, not yet - Mother of child with functional seizures, UK (McWilliams et al., 2016).

A study of 141 patients with functional seizures reported that 12.1% described social stigma with their condition being a preventive factor to socialization (Vaidya-Mathur et al., 2016). Social withdrawal occurred due to many reasons, such as embarrassment around symptoms (Fairclough et al., 2014; Nielsen et al., 2019); fear for others or themselves, or unadapted access to work, school and college environments (Dickinson et al., 2011; Lakhani et al., 2022; Pretorius & Sparrow, 2015; Rawlings, Brown, Stone, & Reuber, 2017; Wyatt, Laraway, & Weatherhead, 2014). For many, this became a vicious circle whereby people completely lost their confidence to go out at all, becoming very restricted or even housebound (Green et al., 2004; Pretorius & Sparrow, 2015; Rawlings, Brown, Stone, & Reuber, 2017; Wyatt et al., 2014).

Other children avoid playing with me because they consider and calls me, 'psycho' (Soumya, India) (Moyon et al., 2021). For adolescents, reports on this theme were particularly concerning. Fear of being exposed to "delegitimizing events" –such as parents and teachers making snide comments about voluntary control, led to the young person hiding their symptoms - which resulted in isolation from several social domains (Karterud, Haavet, & Risør, 2016; Moyon et al., 2021). Due to fear or stigma - children reported not being allowed go out with friends, parents accompanying them publicly, and in some cases, children were not permitted to attend the school or were homeschooled (McWilliams et al., 2016; Moyon et al., 2021). Unfortunately for some young people social exclusion was fuelled by bullying. They [peers] treat us like we're out-casters in a way." (Tanner et al., 2022). This bullying occurred for many reasons – as a result of the nature of the symptoms themselves, teachers singling out children, saying they were faking it or scaring others, or peers taunting them. One teenager used a social media poll to gain understanding of how others viewed her - 48 responded that they viewed her differently because of her functional seizures (Tanner et al., 2022).

Though it was reported that family pressures could be constraining socially, numerous studies also described the benefits of social support from friends and family (Dickinson et al., 2011; Karterud et al., 2016; Rawlings, Brown, & Reuber, 2018; Rawlings, Brown, Stone, & Reuber, 2017).

4.3.3.3. *Subtheme 1b: Employment and driving restrictions.* Before I started having these fits [] I had a job, I had a car, I could drive, I had my—what I thought was independence. [] I could do everything in what I wanted to do, em, and I honestly thought my world had ended. [] {sigh} I've had to completely change my life around - Julie, patient with functional seizures, UK (Green et al., 2004).

Many patients with FND reported not being able to work or having to take extended breaks from work; Carton et al. (2003) reported that 60% of individuals (50/84) cited their functional seizures as obstacles to employment. The symptoms or inability to adapt to the work and academic environment were found to be driving factors in not being able to work or study (Nielsen et al., 2019; Pretorius, 2016). HCPs have mixed feelings towards patients being employed or receiving disability benefits – many considering that employment should be restricted, but also that patients should not be entitled to disability benefits (Asadi-Pooya et al.,

Table 1

Key themes and subthemes with illustrative quotes.

Key theme	Subtheme with illustrative quotes
1. Social Exclusion	1a Socialization Mother: I did have one mum in particular approach me at another child's birthday party ... I was like here it comes, but I won't be inviting X over to our house and I was like okay do you want to explain that, and it was well I think that might be upsetting for my children. - Mother of child with functional seizures, UK (McWilliams et al., 2016)
	1b Employment and driving restrictions The doctor said it would be best, because I work with patients, it's for the best... I stopped working – Patient with functional seizures, South Africa (Pretorius, 2016)
	1c Socioeconomic status HCPs describe PNES as an "expensive condition to have" due to the cost of specialists and the services needed to arrive at the diagnosis - Healthcare professional, Namibia (du Toit & Pretorius, 2017)
2. Self-perception	2a Shame and embarrassment Such hostility [...] I always feel guilty, ghostly, 'failing to get better', etc. I had a (minor) head injury, just glued. I felt so humiliated by her antagonism when I was already emotionally really vulnerable - Participant with functional seizures, online survey (Robson & Lian, 2017)
	2b Self-esteem Attacks make me more subdued because I am scared people will laugh at me, consequently my social world had [sic] diminished – Patient with functional seizures, UK (Carton et al., 2003)
	2c Identity and self-stigma Psychological seizures? Is there something wrong with me? [...] I can't believe that a psychologist could help me. I have always considered myself a happy and positive girl – Patient with functional seizures, Norway (Karterud, Knizek, & Nakken, 2010)
Illness perception	3a Malingering/ feigning I was also told several times I was faking it for attention... not only in the emergency room, also by my psychiatrist - Patient with functional seizures, South Africa (Pretorius, 2016)
	3b Voluntary control ... sometimes there is maybe conscious over-exaggeration... [a patient] was very well walking on the arm of her friend who was very supportive... but when I assessed her on the couch it was much more difficult: she wanted to prove to me that she was really unwell- Neurologist, (Kanaan, Armstrong, Barnes and Wessely, 2009a)
	3c Cultural perceptions [they] feel that they're going to be scorned by the medico-psychological profession if they say they have had exorcism and it hasn't gone away - Healthcare professional, South Africa (Fouché et al., 2019)
Illness status	4a Comparison with neurological condition It's a sense of less importance.... you're nearly praying, please let it be epilepsy- Parent of child with functional seizures, UK (McWilliams et al., 2016)
	4b Comparison with psychiatric condition It's just so annoying that the world is so taboo about mental health full stop. So, when you hear about the Psychiatry side... it's like oh God - Patient with functional seizures, UK (Read et al., 2020)
Professionalism	5a Dismissal They just pretty much write you off and say, 'You know you don't have epilepsy, go see somebody else,' and don't tell you anything, don't give you any suggestions, don't say anything for you. It's very difficult, because they don't; nobody realizes what it's like to be like this. - Patient with functional seizures, Canada (Dickinson, Loooper, & Groleau, 2011)
	5b Prejudice When I get taken to hospital [] they're very rude. [] I feel that they're thinking that I put it all on' (Carol); 'It was the way he (neurologist)—it was told to me—and I felt as if

(continued on next page)

Table 1 (continued)

Key theme	Subtheme with illustrative quotes
	<p><i>they think I was actually inducing them myself—like attention seeking</i> - Patients with functional seizures, UK (Green, Payne, & Barnitt, 2004)</p> <p>5c Harm</p> <p><i>She then bent a pillow around my face, again to try and get a response she put me in a wheelchair with force and started shouting at me and pushing my shoulder and head back into the chair. I was very woozy and didn't understand what was happening...</i> - Participant (patient), with functional seizures, Online survey (Robson & Lian, 2017).</p> <p>5d Cascade of negative attitudes</p> <p><i>With functional symptoms you, you tend to get people who say you don't want to feed into it or, um, you don't want to highlight the issue, you don't really want to do formal assessments. Um, so I think that, that makes it challenging as well because, yeah, as I said, when you're less experienced you kind of think 'well, what should I do then?'</i> - Speech and language therapist, UK (Barnett et al., 2022)</p> <p>6a Wait times</p> <p><i>It took a very long time to get diagnosed and it took some extended time to get a neurologist on board with the data I was presenting.</i> - School nurse, United States (Terry & Trott, 2019)</p> <p>6b Non-deserving of care</p> <p><i>A lot of the time they get thrown out of the hospital, you know, pretty unceremoniously and actually, well, these people still have symptoms and they're not being looked after, and not being treated properly, and I think it's quite awful.</i> - Speech and Language Therapist, UK (Barnett et al., 2022).</p> <p>7a Point of diagnosis</p> <p><i>the most consistent message I'm getting from people is that they don't really understand the disorder, they haven't been given clear information and that it's all in their head</i> - Healthcare provider of psychological therapy, UK (O'Connor & Reuber, 2021)</p> <p>7b Lack of transparency</p> <p><i>the problem we have as physios is often that consultants aren't honest with patients about their true diagnosis which makes our treatment and explanation of symptoms more difficult</i> - Physiotherapist, UK (Evans-Lacko et al., 2011).</p> <p>7c Terminology</p> <p><i>The majority of health professionals refer to the seizures as pseudo, and they translate this as fake. I already feel like a failure due to my inability to control the seizures, these experiences just go on to reinforce these feelings, and have resulted in suicide attempts</i> - Participant (patient), with functional seizures, Online survey (Robson & Lian, 2017)</p> <p>7d Interdisciplinary communication</p> <p><i>it takes me by surprise: is she really suspected of having FND? It is not written anywhere. It is almost as if it is taboo to put it in writing. But the thing is, I would have observed the patient differently [observing for signs of dissociation] if I had known</i> - Healthcare professional, Iceland (Klinke et al., 2019).</p> <p>8a Knowledge and education</p> <p><i>it is very difficult to have information shared so that we can actually advocate for the child...there's minimal conversation...they don't like to send information our way</i> - School nurse, United States (Terry & Trott, 2019)</p> <p>8b Feeling "ill-equipped"</p> <p><i>...we don't necessarily feel we have the skill to deal with some of the psychological elements of the condition</i> - Occupational Therapist, UK (Nicholson et al., 2021)</p> <p>8c Call for training</p> <p><i>we need more information, and we need more coaching, training in terms of this disorder. ...you have to go out of the country for training</i> - Healthcare professional Namibia (du Toit & Pretorius, 2017)</p> <p>9a Stigma as barrier to treatment</p> <p><i>the most commonly identified barriers to the diagnosis and treatment for PNES were stigma/lack of awareness of</i></p>
Not a priority	
Communication	
Knowledge, training and skillset	
Care – access and inconsistencies	

Table 1 (continued)

Key theme	Subtheme with illustrative quotes
	<p><i>PNES (identified in 70% of countries) - Healthcare professionals, multiple countries (Hingray et al., 2017)</i></p> <p>9b Lack of available expertise</p> <p><i>I...felt like I was just pushed out to sea and left to build a raft on my own.</i> Adolescent with functional seizures, USA (Tanner et al., 2022).</p> <p>9c Call for services</p> <p><i>a network of clinical psychologists in the country... who are proficient in this area</i> - Healthcare professional, South Africa, (Fouché et al., 2019)</p> <p>10a Interventions</p> <p><i>After completing the workshop, nearly all endorsed that functional symptoms are "real" (95%) and that treatment is helpful (100%)</i> - Healthcare professionals, United States (Medina et al., 2021)</p> <p>10b Shared understanding - believed and supported</p> <p><i>What was clear was that her individual experience had never really been acknowledged or listened to or explored. And having that experience of me doing that with her helped her start to be in different relationship with herself</i> - Healthcare provider of psychological therapy, UK (O'Connor & Reuber, 2021)</p>
Anti-stigma	

2021; Asadi-Pooya, Dastgheib, & Nazeri, 2020; Lehn et al., 2019). One study showed 16% out of a total of 516 HCPs agreed that patients with functional seizures should not be awarded disability pension as it would stop them getting better (Lehn et al., 2019). In a large survey of 565 doctors, (residents and early consultants) while 84.8% ($n = 479$) responded that FND was a real disease, only 34.9% ($n = 197$) thought that these patients should benefit from disability recognition (de Liège et al., 2022). These studies showed that many HCPs considered patients unfit for certain occupations yet at the same time, also undeserving of welfare benefits, which raises the question of how patients with FND are likely to be at a financial disadvantage. In a Chinese study of 102 HCPs, 97.1% said that patients would not be entitled to receive disability benefits because of their functional seizure diagnosis (Tong, An, Reuber, Zhang, & Zhou, 2018).

The majority of HCPs believed that driving should be restricted for patients with functional seizures (Dastgheib et al., 2020; Sahaya, Dhoklakia, Lardizabal, & Sahota, 2012). Driving with FND is understandably a contentious area, as driving could be unsafe with functional seizures, and so prohibiting driving is not meant to stigmatize, but nevertheless contributes to social exclusion in car-dependent societies. A study of 141 patients diagnosed with functional seizures showed the most important barrier to socialization was not being able to drive (Vaidya-Mathur et al., 2016); and numerous reports describe how being unable to drive contributed to social exclusion, isolation and loss of freedom and independence (Carton et al., 2003; Pretorius, 2016; Rawlings, Brown, Stone, & Reuber, 2017).

Numerous studies of clinicians' perspectives describe how they do not know what to advise patients, and how driving regulations need to be made clearer (Farooq et al., 2018; Kanaan et al., 2021). A consensus report on the topic showed that most HCPs felt that decisions about driving privileges should consider the individual patient and characteristics of their functional seizures, and take into account private or commercial driving (Asadi-Pooya et al., 2020).

4.3.3.4. Subtheme 1c: Socioeconomic status. *There is a Neurologist who has to make the diagnosis... it's quite difficult because they have long waiting periods and the costs of accessing their services can be quite high and not all patients can actually afford to pay for those services* - Healthcare professional, Namibia (du Toit & Pretorius, 2017).

Socioeconomic status was outlined as a barrier to diagnosis and treatment in numerous studies. In a survey of HCPs from 63 countries, lack of money for treatment (60%) was the main barrier to treatment (Hingray et al., 2017). Lack of money for psychotherapy was perceived

as a difficulty by 30% of a survey of 62 mainly epileptologists (Carter et al., 2018). In a survey of HCPs in Namibia, lack of financial means for an appointment with a seizure expert (48%) and lack of money for psychotherapy (40%) were outlined as significant barriers (du Toit & Pretorius, 2018). In Latin America, inability to pay for psychotherapy (57%), diagnostic tests (48%), appointments (45%), or drug treatment (41%) were reported as the most common difficulties regarding access to services (Ladino et al., 2021). A Chinese study reported that illiteracy was a common barrier to accessing diagnostic or treatment services for patients with functional seizures (Tong et al., 2018). HCPs in Namibia described functional seizures as an “expensive condition to have” and patients often could not find they could afford specialist services, (du Toit & Pretorius, 2017) with similar patient reports from India (Lakhani et al., 2022). Lack of funding for therapies such as speech and language therapy, occupational therapy, psychological therapy and physiotherapy, were also identified as hurdles in rural parts of England and Scotland (Nicholson et al., 2021). Socioeconomic status is more than not just having money to pay for treatment but is impacted by lack of ability to attend education and work – areas where patients with FND are already disadvantaged.

4.3.4. Theme 2. Self-perception

Self-perception is associated with internalised (self) stigma and perceived stigma, under which the following subthemes manifested: a) shame and embarrassment, b) self-esteem and c) identity.

4.3.4.1. Subtheme 2a: Shame and embarrassment. *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* - Lisa, patient with functional motor symptoms, UK (Nielsen et al., 2019).

Patients described how their FND symptoms set them apart from others – and embarrassment led to avoidance of socialization or attending treatment (Fairclough et al., 2014; Karterud et al., 2010). Some of this embarrassment, and also shame, seemed to stem from being labelled with a “psychiatric diagnosis” (Karterud et al., 2010; Rawlings, Brown, Stone, & Reuber, 2017). A type of “double stigma” existed for some – the stigma of having a seizure disorder and being “ashamed” of a mental health diagnosis (Rawlings, Brown, Stone, & Reuber, 2017). Concealment of their condition occurred to avoid the negative opinions of others – (Bazydło & Eccles, 2022; Karterud et al., 2016). Parents, while well-meaning, seemed to play a part in perpetuating this cycle, such as insisting on accompanying their children on public transport or restricting social activities, leading to loss of friendships (McWilliams et al., 2016). Furthermore, negative self-image for children was also increased when parents reported being embarrassed by their children's symptoms (Karterud et al., 2016).

HCP interactions were sometimes crude and dismissive, and added to the sense of shame and humiliation that patients experienced (Bazydło & Eccles, 2022; Rawlings, Brown, Stone, & Reuber, 2017; Robson & Lian, 2017). *“I had a GP say to me: ‘[it's] a unicorn condition’ which I found quite offensive... I was taken aback and didn't say anything but I wish that I had” (Hannah).* (Bazydło & Eccles, 2022). HCPs too, seemed to collude in a cloak of secrecy around the diagnosis; *“they kept the diagnosis hidden from him. It seemed to me that they were almost ashamed on his behalf...they just tiptoed around the patient, not informing him what the matter was” (Klinke et al., 2019).* Professionals too experienced self-blame *“I remember having the feeling that well maybe I should know what I'm doing but I just don't. ... maybe I should've learnt this at uni [...]” (Barnett et al., 2022).*

4.3.4.2. Subtheme 2b: Self-esteem. *I am a different person. I am weak, fat and useless* – Patient with functional seizures (Rawlings, Brown, Stone, & Reuber, 2017).

Self-confidence was reduced in 63% of responses (53/84) of patients

who had their diagnosis changed to functional seizures from epilepsy (Carton et al., 2003). A Turkish study found that adolescents with functional seizures reported significantly lower levels of self-esteem than patients with epilepsy and healthy controls, and that these patients experienced significantly more relational problems, and were more likely to have a history of abuse and trauma (Say et al., 2014). Dimaro et al. (2015) studied individuals with functional seizures (30), epilepsy (25), and healthy controls (31) and found that patients with functional seizures had lower explicit self-esteem than those with epilepsy or healthy controls. The reasons for low self-esteem were not explored in depth in these quantitative reports, however qualitative studies from the patient perspective show how perceived stigma and humiliating interactions with HCPs may contribute to low feelings of self-worth, with patients describing themselves in derogatory terms; *“loser”, “pathetic” and a “waste of space” (Rawlings, Brown, Stone, & Reuber, 2017); just felt stupid, silly, and people didn't understand; people thinking I were just taking the piss. I couldn't tell them how I felt coz I couldn't understand myself (Dosanjh et al., 2020).*

4.3.4.3. Subtheme 2c: Identity and self-stigma. *I just didn't want to do anything that was going to embarrass me... you just feel helpless... a burden... What is the point of me when I'm like this... a waste of a life. I was no use, to anybody. I just thought I was worthless.* - Woman with functional movement disorder, UK (Dosanjh et al., 2020).

On a practical level for many patients the symptoms interfered with work, study and social life, thus threatening autonomy and independence (Pretorius, 2016; Rawlings, Brown, Stone, & Reuber, 2017; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). This subsequently led to patients' worlds shrinking, a lack of self-worth and the self-stigma associated with being forgotten – *“being on the scrapheap” (Fairclough et al., 2014).* For some the stigma they internalised was perceived stigma from others, including HCPs, impacting their self-identity and presenting a barrier to treatment engagement. *“You kind of start doubting yourself...questioning yourself a lot. Am I actually? Is it my fault that I'm having these seizures? (Staton et al., 2023).* Being labelled with a mental health diagnosis was also perceived as a threat to patients' identity; *“normal people don't go to therapy” (Pretorius & Sparrow, 2015); and engendered self-stigma. For many the idea of having something “psychogenic” posed a threat to their self-image and self-understanding – this realm of the diagnosis was so disturbing to their existing self-concept that they were unable to accept it (Karterud et al., 2010, 2015). ‘[colleagues] don't know about what the condition is... I didn't tell them. I didn't want to appear weak... I liked being good at what I did and I didn't want anyone to think that I couldn't perform my job’ (Bazydło & Eccles, 2022).*

On a positive note, many found peer support and identifying with other patients helpful (Dickinson et al., 2011); and enhanced their sense of self-worth in psychological therapy (O'Connor & Reuber, 2021; Rawlings, Brown, Stone, & Reuber, 2017). Some eventually learned to accept their condition as a valid and integrated part of themselves (Wyatt et al., 2014).

4.3.5. Theme 3. Illness perception

Several reports from a patient perspective and HCP perspective reported on illness perception, with emergence of the following subthemes; a) malingering/feigning, b) voluntary control and c) cultural perceptions of illness.

4.3.5.1. Subtheme 3a: Malingering/feigning. *I got angry when doctor said that it was a drama. Why would I do that? Why would I come here? (Roy). I felt awful when teacher told me that I was pretending to be ill, why me? (Priya)* - Adolescents with FND, India (Moyon et al., 2021).

Attitudes towards malingering were quite mixed and this topic was rarely conceptualised in a straightforward way. HCPs often perceived a blur between patients malingering, exaggerating, and having some but not full conscious control over their symptoms.

In a large study of psychiatrists (total $n = 963$), 45% reported that functional seizures could be caused by a “need to seek attention”, and 10% considered them as a type of voluntary behavior related to malingering (Aatti et al., 2016). In an older study of mixed HCP (total $n = 115$, of which 39 were nurses), 48% of nurses felt that functional seizures are ‘fake’ and patients have voluntary control over them (Sahaya et al., 2012). A survey of 183 psychiatrists found that 56% regarded there to be an overlap with “Conversion Disorder” and feigning, but a small minority (2%) thought that feigning was the full etiology in its own right. They compared these answers to a previous survey by neurologists, finding that relatively fewer psychiatrists saw feigning and conversion disorder as completely distinct and fewer patients were considered to be feigning compared with neurologists (Dent et al., 2020). In a more recent study of psychiatrists in Italy, 71% ($n = 123$) of respondents believed that intentional production of symptoms was a little probable and 16% ($n = 27$) considered it moderately probable (Marotta et al., 2023). In a similar survey of neurologists in Italy, 67% ($n = 328$) of respondents believed that intentional production of symptoms was a little probable and 27% ($n = 131$) considered it moderately probable (Tinazzi et al., 2021).

In a survey of pediatric doctors ($n = 61$), 18% indicated the children faked their symptoms and interestingly, responses did not vary significantly based on the degree of clinical experience (Nielsen, Wichaidit, Østergaard, & Rask, 2018). In a survey of 159 GPs, and internal and emergency physicians, 38% believed that functional seizures were “voluntarily induced (patients are fakers)”, with emergency physicians more likely to believe events were induced voluntarily (Shneker & Elliott, 2008). In a survey of neuroscience nurses’ attitudes ($n = 68$) towards “conversion symptoms”; 16% ($n = 11$) disagreed that conversion symptoms were “real”; (Ahern, Stone, & Sharpe, 2009). In a large survey of physiotherapists ($n = 702$), 45% of the respondents felt that over 20% patients were partially feigning, and 21% felt that over 20% patients were completely feigning (Edwards, Stone, & Nielsen, 2012). A recent study of psychiatrists in Egypt – 52/152(34%) agreed that they were “often worried patients were actually malingering/faking/feigning” (Alamrawy et al., 2023).

A study of speech and language therapists revealed some multidisciplinary members thought functional stroke and malingering were interchangeable terms, with patients regularly being called “fakers” and “after attention” (Barnett et al., 2022). These beliefs also extended to school staff and school nurses (Terry & Trott, 2019). In a qualitative study of 22 neurologists’ views on “conversion disorder” neurologists were evenly divided on whether conscious feigning was a factor in the presentation (Kanaan, Armstrong, Barnes and Wessely, 2009a).

From the patient perspective, in a study of individuals with functional seizures, 36/75 (48%) reported that other people think they are faking their seizures (Arain et al., 2016). Some patients got the impression that HCPs thought they were faking it without it being said explicitly (Fairclough et al., 2014; Green et al., 2004) – “a sense of being disbelieved” (Wyatt et al., 2014). There was evidence of anticipated stigma from HCP for many patients, including adolescents, threatening their identity and credibility “then the results of ...tests are normal, then I am sure that the doctor thinks that I’m making up stories and fantasizing (...). I do not want people to think I’m a bad person because I suffer from seizures” (Karterud et al., 2015).

On a more extreme level, some patients reported that HCPs explicitly told them they were malingering (Pretorius, 2016; Pretorius & Sparrow, 2015; Rawlings, Brown, Stone, & Reuber, 2017; Robson & Lian, 2017). Similar themes prevailed – they were accused of doing it for attention, making it up and that their seizures were not real (Lakhani et al., 2022; María Marta et al., 2023). The feeling or indeed accusations of being disbelieved extended beyond HCPs to friends, family and teachers (Karterud et al., 2016; McWilliams et al., 2016; Rawlings, Brown, Stone, & Reuber, 2017). “Young person: “I got into trouble the next day. She (a teacher) said that I played her just to get out of having a test and I faked having a fit” (McWilliams et al., 2016).

4.3.5.2. *Subtheme 3b: Voluntary control. I can control what happens to me inasmuch as I can make myself safe, and make my child safe. But the rest of it, I’ve got no control over* - Shirley, patient with functional seizures, UK (Green et al., 2004).

Numerous surveys of HCPs demonstrate that many of them (though not the majority) regard functional seizures as something that can be somewhat controlled by the patient. This seemed distinct from deliberate feigning; and there was some uncertainty and a spectrum represented here about how much the patient could control their symptoms. These views contrasted with the patients’ views, and differed between specialties.

A survey of 32 psychiatrists and 37 neurologists found that only 10% ($n = 7$) of people answered “they do not respond intentionally (voluntarily)” when asked what happens during an episode (Dastgheib et al., 2020). Whitehead et al. (2013) compared the patient and neurologist illness perceptions of patients with functional seizures and epilepsy, finding that in both conditions neurologists thought patients had higher levels of treatment-related and personal control of their condition than did the patients themselves (and that they had more control in relation to functional seizures). Whitehead and Reuber (2012), evaluated illness perceptions of neurologists and psychiatrists, finding that both groups considered that patients with functional seizures had greater personal control over their condition than patients with epilepsy, with both groups of doctors highlighting greater understanding of epilepsy compared with functional seizures.

Worsely, Whitehead, Kandler, and Reuber (2011) examined illness perceptions of emergency care staff and neuroscience ward staff comparing epilepsy and functional seizures. Both groups considered patients with functional seizures to have more personal control of their seizures compared with epilepsy, with many emergency care staff attributing functional seizures to “alcohol or behavioral issues”. The main difference between the two staff groups was that the “patient’s own behavior” was endorsed as the main cause by 90% of emergency care staff and only 64.5% of neurology ward staff. In a study of neuroscience nurses, (total $n = 68$), 21% (14) considered that people with functional symptoms were in control of their symptoms (Ahern et al., 2009). In a survey of 120 GPs, 53.3% agreed that or did not know whether patients had voluntary control over their functional seizures (Yogarahaj et al., 2018).

Thematic reports showed the distress caused by the experience of loss of control (Fairclough et al., 2014; Green et al., 2004). “Seizures were described as unpredictable and uncontrollable during which participants felt ‘powerless’ and ‘incapacitated’” (Fairclough et al., 2014). These feelings seemed to be further fueled by the uncertainty around the helpfulness of treatments and exclusion in relationships with HCPs. For many the idea that the seizures were no longer epilepsy implied they could now control them, which did not fit at all with their experience, leading to patients feeling confused and invalidated (Robson & Lian, 2017; Wyatt et al., 2014).

Some patients felt that perhaps they could have more control, but they did not know how “If I can make myself have these attacks then I can make myself stop them” (Green et al., 2004). Of note, the authors of this paper are aware there might be a minority of patients with functional seizures who can in some instances “succumb” to their inevitable seizure to escape their unbearable prodromal symptoms (Stone & Carson, 2013). For some, the implication of having voluntary control was not seen as negatively as others – “I was relieved to hear that my seizures were not due to epilepsy. Now that I know that I can influence the attacks myself, I know that it is not a “closed case” (Karterud et al., 2010).

In a content analysis of differing views of media, medical group literature and patient groups, all the source groups, especially the patient groups considered that symptoms of FND were not under volitional control, however the medical group had the most sources implying that symptoms were able to be controlled by the patient on some level (Carruthers et al., 2021).

4.3.5.3. *Subtheme 3c: Cultural perceptions of illness. when I went to the emergency room, for example, the nurses grabbed me, they told my mother to go to an exorcist. Those things hurt me.* Woman with functional seizures, Argentina, (María Marta et al., 2023).

In a large survey of 519 neurologists 40% stated that “cultural beliefs about psychological illness” were a main barrier to managing patients with functional motor symptoms (Espay et al., 2009), which increased to 50% in a follow up study (total $n = 864$) (LaFaver et al., 2020). In some geographical areas, functional seizures were equated with something “bad” - such as the patient had been cursed, or was the result of magic, bad energy and witchcraft (María Marta et al., 2023; Moyon et al., 2021). It was sometimes the case that the patient themselves did not believe this, but this was the belief of their relatives or community (Sarudiansky et al., 2017). In cases where the patient may have sought a folk treatment or some such, they were afraid of communicating this to their medical team in case they were met with scorn or dismissal (Fouché et al., 2019). For some patients and their families - their satisfaction with their doctors was low and hence they resorted to “faith healers”; “my parents take me to the temple. They perform some rituals on me to make it go away” (Lakhani et al., 2022). The role of culture and stigma in relation to treatment was also relevant - for example in Namibia- talking about the self is less culturally acceptable, not important and something to be evaded; and CBT techniques could be perceived as “confrontational” (du Toit & Pretorius, 2017).

Regarding illness perception of FND in the media -one study identified 13 probable cases of FND in news stories that were reported as other medical conditions (in 11 cases) or “medical mysteries”. Media misrepresentation like this potentially adds to stigma and is a missed opportunity conversely to portray FND as a common and treatable condition that is not mysterious (Popkirov et al., 2019). One study examining illness representations of functional seizures and epilepsy from the general public perspective found that “biopsychosocial framings” of functional seizures led to an impression of the condition being more threatening than “biomedical framings” (Coey et al., 2023). Regarding online social media, one review of how functional seizures was searched and described revealed derogatory themes towards patients with functional seizures: “self-identified professional tweets using the keyword ‘pseudoseizures’ revealed tweets that were pejorative and negatively biased ... Language was extremely coarse and offensive in some of these tweets” (Myers et al., 2016).

4.3.6. Theme 4. Illness status

FND was seen not to have the same status as other disorders to which it was commonly compared, revealing themes of prejudice, stereotyping, and social distance. The following subthemes emerged in relation to illness status: a) comparison with conditions seen in neurology, and b) comparison with conditions seen in psychiatry.

4.3.6.1. *Subtheme 4a: Comparison with neurological conditions. If only I had epilepsy, then I would be offered help from a multi-professional team at the epilepsy centre. With PNES, I feel I'm on my own, and dealing with the attacks is my own responsibility* - Woman with functional seizures, Norway (Karterud et al., 2010).

This status loss was especially relevant for patients who had a diagnosis changed from epilepsy to functional seizures (Carton et al., 2003; Karterud et al., 2010; Pretorius, 2016). Patients experienced a mix of emotions, from confusion to anger to a sense of being a fraud (Carton et al., 2003; Green et al., 2004; Karterud et al., 2010). It is possible that self-stigma drove some of these responses in addition possibly to how the diagnosis may have been delivered. Many patients felt disregarded; “they just pretty much write you off and say, ‘You know you don’t have epilepsy, go see somebody else,’ and don’t tell you anything” (Dickinson et al., 2011). Parents reported that if it was epilepsy, they would have better support and access to treatment “It’s a sense of less importance.... you’re nearly praying, please let it be epilepsy” (McWilliams et al., 2016);

or were told to be grateful it wasn’t epilepsy (Peacock et al., 2023).

Similarly with multiple sclerosis (MS) and stroke, disparities in care - both service availability and professionalism, were evident (Barnett et al., 2022; O’Keefe et al., 2021). In a service evaluation study comparing 40 patients with FND and 37 with MS; those with FND reported significantly longer waiting times for diagnosis, more patients with FND felt that they were not involved in their care decisions and that their wishes were not taken into account. More FND respondents felt their needs were not understood by clinicians and also significantly more that they felt they were not treated with respect and dignity. Of note no respondents with MS in this study reported feeling they were not treated with dignity and respect by any HCP (apart from hospital consultant) (O’Keefe et al., 2021). Numerous reports from HCPs also outlined how they felt that FND was not highly prioritised compared with other conditions with the absence of cohesive care pathways (Barnett et al., 2022; Klinke et al., 2019; Nicholson et al., 2021).

In a study examining HCP attitudes of legitimacy towards FND and MS, participants reported strong explicit FND-legitimate and MS-legitimate attitudes but demonstrated an implicit FND-illegitimate/MS-legitimate bias. Medical doctors, compared with psychologists, displayed stronger explicit attitudes that FND is illegitimate. Interestingly in this study, attitudes about FND-illegitimacy were negatively associated with lesser likelihood of referral to physiotherapy (Begley et al., 2023).

4.3.6.2. *Subtheme 4b: Comparison with psychiatric conditions. This is an unfair diagnosis. There isn’t any help and I won’t be respected. At the emergency reception they say, just let him lie there and shake, it is only psychiatric* - Patient with functional seizures, Norway (Karterud et al., 2010).

There was an impression among patients that having “normal investigations” equated to mental health issues, which were not worth further management, leading to patients feeling rejected (Karterud et al., 2010; Robson & Lian, 2017; Wyatt et al., 2014). In a study of 75 patients, one third thought a diagnosis of “PNES” meant being “crazy” (Arain et al., 2016). Several patients reported that when professionals regarded their functional seizures as a mental health issue there was a lack of respect, support and outright dismissal; “In my experience many doctors were not supportive or empathetic when they realised that it was a mental health problem and not a medical issue” (Pretorius, 2016).

The concern around equation with a mental health diagnosis led to self-stigma for patients (Read et al., 2020), leading to them not disclosing the diagnosis (Karterud et al., 2016). Some pretended their condition was something else - such as epilepsy (McWilliams et al., 2016); a “natural tremor”, or “brain injury” (Bazydlo & Eccles, 2022). Cultural beliefs as described around mental and neurological illness as something dangerous was something to be avoided was evident (du Toit & Pretorius, 2017). In a study of patients with functional motor symptoms- the idea of a psychological cause was viewed as a personal defect, with some distancing what they perceived to be a pejorative stereotype; “[I’m] not that type of person” (Nielsen et al., 2019).

HCPs reported, similarly, the status loss with a functional diagnosis, which could lead to difficulties therapeutically (Barnett et al., 2022; McMillan et al., 2014; O’Connor & Reuber, 2021). In an analysis of film recordings of doctors, patients and caregivers discussing the diagnosis, doctors “pre-empted” this status loss - “It’s not worth less because it’s psychological, yeah?”. Irrespective of what these HCPs intended to communicate, there was a sense that because of the “psychological element”, the illness was not considered as real or important (Robson & Lian, 2016). Peacock et al. (2023) discuss the difficulties around the “dominance of biomedicine” and how any psychologically oriented explanations offered to patients do not adequately account for the nature of their symptoms - leading to uncertain identity, social position and ultimately furthering “illegitimacy”.

4.3.7. Theme 5. Professionalism

There were several reports outlining the disturbing attitudes and actions of professionals working with patients with FND. Subthemes that arose included a) dismissal, b) prejudice, c) harm and d) cascade of negative attitudes.

4.3.7.1. Subtheme 5a: Dismissal. *Even actually in the patient's home sometimes, you know a sense from the paramedics that they're wasting their time and Oh, god, it's you again! And then left hanging around in emergency rooms and then and then when they hit the wards, you know, the nurses tutting and then the doctors not being able to give them any kind of coherent explanation. So, yeah, it can be it can be horrible.* -Provider of psychological Therapy, UK, (O'Connor & Reuber, 2021).

Dismissal for patients ranged on a spectrum of mild disinterest, to more blatant disregard to outright rejection (Dickinson et al., 2011; Fairclough et al., 2014; Hutchinson and Linden, 2021; Lakhani et al., 2022; Peacock et al., 2023; Pretorius, 2016; Zeun & Hunter, 2023). For some this experience impacted motivation to seek treatment (Dickinson et al., 2011), an issue also noticed by HCPs (du Toit & Pretorius, 2017). While most of these studies involved patients with functional seizures, studies evaluating experiences of patients with Functional Motor Disorder (FMD) similarly reported perceptions of negative attitudes, conflict and poor treatment - which they felt occurred on receipt of a "psychogenic diagnosis" (Nielsen et al., 2019); and that these attitudes resulted in them not being referred for physiotherapy (Zeun & Hunter, 2023). Some were worried that FND would be a "write off" diagnosis, hampering future care: 'Now it's on my medical record, I am really concerned that if I do have a stroke—because I can still get strokes or anything else—they're gonna just assume it's FND and write me off' (Bazydło & Eccles, 2022). Emergency care services (ambulance and emergency department staff) were often described as being more explicit in their expressions of dismissal and derision (O'Connor & Reuber, 2021; Robson & Lian, 2017).

4.3.7.2. Subtheme 5b: Prejudice. *People's attitudes towards these patients is often really negative and dismissive, [...] not really giving them the time of day, being annoyed that they're there really, if I can be frank, and just wanting them out* - Speech and language therapist, UK (Barnett et al., 2022).

Prejudice is a type of stigma involving an emotional response, which may or may not lend itself towards harmful interactions. In a survey of 864 HCP from 92 countries, 29% of respondents reported somewhat or very much disliking seeing FND patients (LaFaver et al., 2020). In an older study of neurologists some reported making a diagnosis based on a criterion that the patient was "dislikeable" (Kanaan, Armstrong, & Wessely, 2011) and a survey of neurologists have reported FND as one of the disorders they least like to treat (Evans and Evans, 2010). A study of 68 neuroscience nurses - 72% (49) concurred that staff view FND patients in a negative light, with 46% (31) reporting patients to be "manipulative" (Ahern et al., 2009), and in this study, 7% (5) did not think FND patients were deserving of the same level of care, and 24% (n = 16) agreed that patients with FND were annoying. In an Australian study of HCPs (total n = 516), 39% agreed they found patients difficult and demanding, and 10% found them manipulative. In this study negative attitudes correlated with increasing age and more years of practice, less clinical interest, less communication confidence and finding it more difficult to help patients with FND (Lehn et al., 2019). In an Israeli study of 47 mixed HCPs surveying emotional attitudes towards functional seizures, 62% of the participants agreed that this patient group arouse anger among medical staff, 60% of participants agreed this group were treated with disrespect, and 50% agreed this group misuse medical resources and are their cases are less urgent, with no correlation regarding negative emotional attitudes and participants' department, occupation, or seniority (Saker et al., 2022). In a study of professionals caring for FND in Veterans, many acknowledged their prejudices,

attributing much of it to what they inferred as disability seeking or "gaming the system" (McMillan et al., 2014).

4.3.7.3. Subtheme 5c: Harm – intentional and unintentional. *The doctor told me I was faking. He stabbed my arms with a needle whilst I was paralyzed to prove I was faking* - Patient with functional seizures, (Robson & Lian, 2017).

Some patients described particularly disturbing examples of maltreatment which could be described as assault; Patients reported being pinched and pricked with needles ... (Robson & Lian, 2017). Parents and children felt bullied and mocked by staff: "They bullied X, the staff bullied my son, they were rude to us...X would be in the corner and just had a seizure wetting himself and it was, we're not going to do any more of those are we X" (McWilliams et al., 2016). One patient described treatment with physiotherapists on the ward being akin to "torture"; "other participants were admitted and provided with physiotherapy on the ward, but they felt that it was not helpful and sometimes felt harmful"; (Zeun & Hunter, 2023). Furthermore, though we recognise this is not deliberate harm or cruelty, the misdiagnosis of epilepsy and persistent use of anti-epileptics, in both adults and children (McWilliams et al., 2017) are also harmful, especially given that the majority of patients with FND are women of childbearing age; "But for some or other reason the pills made me sicker, not better... I think the medication was the worst...because it makes you feel really clumsy and confused" - Patient with functional seizures, South Africa (Pretorius, 2016).

4.3.7.4. Subtheme 5d: Cascade of negative attitudes. *They were also convinced that the negative attitudes that emerged when they were exposed to colleagues who disparaged the disorder, could be prevented with proactive education: "I received this knowledge before I had really encountered any patients with FND. I think that this is the reason why I have never experienced that these patients are particularly difficult to deal with in comparison with other neurological patients"* - Physiotherapist, Iceland (Klinke et al., 2019).

Negative attitudes regarding FND cascade through the professional healthcare community (Barnett et al., 2022; Fouché et al., 2019; Klinke et al., 2019). Younger HCPs noted negative attitudes emerged only when they were exposed to the disparaging comments of their colleagues, despite them initially regarding FND as a disorder that required a lot of attention and importance (Klinke et al., 2019). A report of SLTs revealed mixed attitudes - with many reporting that their colleagues dismissed them, and feeling sympathy for FND patients who they felt got the "short shrift". It was noted that "bad habits" were passed down from senior HCPs - some suggesting deceiving patients about treatment, or not giving them care "as not to feed into it" (Barnett et al., 2022). Occupational therapists underwent similar moral dilemmas around level of input/resources to be provided; "Because there is a kind of, 'Oh, we shouldn't give equipment to functional patients', it can be a challenge at home because actually sometimes they need that bit of equipment because they're not actually able to achieve their goal otherwise" (Nicholson et al., 2021).

On a positive note; Marotta et al. (2021) found in their study of 133 GPs that largely, GPs indicated a reasonable level of satisfaction with this group of patients -the majority (n = 93, 70%) rated their level of satisfaction between 5 and 10 (0 not at all satisfied, 10 extremely satisfied). This satisfaction level did not correlate with age or years of practice. A recent similar survey of psychiatrists found that most respondents (n = 134, 77%) rated their level of satisfaction between 5 and 10, with an overall average score of 5.9 (Marotta et al., 2023).

Other HCPs outlined positive attitudes towards patients with FND and/or derived satisfaction from treating them (Fouché et al., 2019; McMillan et al., 2014; O'Connor & Reuber, 2021). Similarly, patients described positive encounters with HCPs where they felt validated and understood (Karterud et al., 2010, 2016; Nielsen et al., 2019; Thompson et al., 2009).

4.3.8. Theme 6. Not a priority

Patients with FND were considered not to be a priority in relation to getting a diagnosis or treatment, and while we recognise this is a complex issue, it relates to institutional discrimination – intended or unintended. Two subthemes were found here; a) wait times and b) non deserving of care.

4.3.8.1. Subtheme 6a: Wait times. It took about three years to diagnosis, before we got a neurologist to look at you seriously - (Ben) Partner of patient with functional seizures, UK, (Wyatt et al., 2014).

Compared with MS, patients with FND reported waiting significantly longer than respondents for both a specialist consultation and a definite diagnosis (time not specified) (O’Keefe et al., 2021). Examining more specific studies that looked at time to diagnosis, for adults the mean time from onset of symptoms to diagnosis of functional seizures ranged from three years (Asadi-Pooya & Tinker, 2017; Goldstein et al., 2020) to over six years (Tinazzi et al., 2021), to nearly nine years (de Timary et al., 2002). The main factors associated with delay in diagnosis included being female (Arain et al., 2016); a diagnosis of head trauma (Asadi-Pooya & Tinker, 2017); anti-seizure medication (Bahrami et al., 2019; Kerr et al., 2016, 2021; Reuber, Fernandez, Bauer, Helmstaedter, & Elger, 2002), history of ictal injury (Bahrami et al., 2019), age of onset (Bahrami et al., 2019; Reuber et al., 2002); and history of physical abuse (Kerr et al., 2021).

Regarding diagnostic delay in children, one study reported the average time between seizure onset and referral was 18 months, with children who had a history of psychological abuse being diagnosed later (Valente et al., 2017a). The delay in diagnosis was “convoluted and stressful” for patients and their caregivers (McWilliams et al., 2016) and a source of dissatisfaction and distress (Crimlisk et al., 2000). It was also a source of concern for HCP who called it “costly and time consuming” (du Toit & Pretorius, 2017). A study comparing diagnostic delay for patients with FND with other neurological disorders, found a higher diagnostic delay in the FND group compared with the other neurological disorders group (FND median = 48 months versus median = 12 months), with diagnostic delay correlating significantly with total costs in the entire sample, more strongly in the group with FND (Cuoco et al., 2022).

4.3.8.2. Subtheme 6b: Not deserving of care. I was discharged without any explanation...you just feel like you have been dumped - Patient with functional seizures, UK (Thompson et al., 2009).

Despite the chronic disability and distress associated with FND, patients were often only seen as a “one off” without any sort of care plan. Our review indicated follow up for patients with FND by neurology is very variable. An older study of 168 British neurologists revealed that 60% sent a majority of these cases “straight back to the referrer” (Mace & Trimble, 1991). A survey of 130 HCPs (mainly neurologists) almost one in five reported they discharged their patients when they made the diagnosis (Mayor, Smith, & Reuber, 2011). More recent studies reported that follow up from neurology was provided for over 50%–75% of their patients; (Carter et al., 2018; Hingray et al., 2017; LaFaver et al., 2020).

Follow up was more frequent in high-income countries compared to middle- or low-income countries (Hingray et al., 2017). In a report of 360 HCPs from 17 Latin American countries, only one-third of HCPs indicated that they provided follow-up patients with a diagnosis of functional seizures as a matter of routine (Ladino et al., 2021). Factors influencing follow up were if the patient had comorbid epilepsy and or were on anti-epileptic medications, and those who were awaiting mental health care were more likely to be discharged (Carter et al., 2018; Tong et al., 2018). In a study of HCPs providing care to Veterans with functional seizures, HCPs noted that patients were rarely welcomed in neurology or psychiatric clinics “nobody wants to deal with them” (McMillan et al., 2014). HCPs outlined their frustrations and challenges arising with this approach; (Barnett et al., 2022; McMillan et al., 2014; O’Connor & Reuber, 2021).

Reports evaluating the perspective of the patient outline the consequences of this treatment. A retrospective study of 64 patients with FMD symptoms evaluating their pattern of care over six years showed they were met with inconsistent pattern of care, puzzlement by doctors, and unnecessary re-referrals (Crimlisk et al., 2000). Patients described feeling alone, shuffled around, uncertain and helpless, and a sense of being let down by the healthcare system. A common theme was the perception of being in limbo, cast aside or abandoned (Dickinson et al., 2011; Fairclough et al., 2014; Lakhani et al., 2022; McWilliams et al., 2016; Nielsen et al., 2019; Thompson et al., 2009). “You just don’t fit into the little tick box that that you need to be in, I guess it’s funding and it’s so frustrating, from both sides, really frustrating. One of the things about FMD is that it’s just so isolating I found the whole NHS system really isolates people ... there was just every door closed, you know, you don’t tick any the boxes so you can’t use their services so it’s it’s so demoralising when that happens” (Zeun & Hunter, 2023).

4.3.9. Theme 7. Communication

Communication, especially between patient and HCP produced four subthemes relevant to stigmatizing experiences; a) point of diagnosis, b) lack of transparency, c) terminology, and d) inter-disciplinary/inter-agency communication.

4.3.9.1. Subtheme 7a: Point of diagnosis. Until there is more understanding of the condition and how to explain things to anyone diagnosed then it’s a lost world I seem to have been put into. - Patient with functional seizures, UK (Rawlings et al., 2018).

The point of diagnosis manifested as a significant area of both difficulty but also enlightenment for patients, particularly those who had a change in diagnosis. In a mixed method study of 84 patients, the most frequently reported reaction was confusion (38%); and even the third that reported some understanding of the diagnosis still experienced a lack of clarity (Carton et al., 2003). Parental reactions showed that 16% (5/30) felt HCPs had not established good rapport at the time of initial diagnosis, with a majority reporting a need for better HCP communication (de Gusmao et al., 2014). Some patients felt that they were diagnosed in a “categorical or paternalistic manner”; whereby their own experience of their condition was not considered (Fairclough et al., 2014; Karterud et al., 2010). Patients described how they preferred more information and support at point of diagnosis - one group reported that the diagnostic point influenced their seizure frequency – both positively and negatively (Rawlings, Brown, Stone, & Reuber, 2017). Many patients experienced either doubt, confusion lack of understanding at this point which furthered isolation and distress (McWilliams et al., 2016; Rawlings et al., 2018b; Thompson et al., 2009).

From the HCP perspective – this theme was mirrored in their difficulties around the interactions; a large Australian study ($n = 516$) 34% agreed with the statement “I often struggle with the discussion of associated psychiatric/psychological problems” (Lehn et al., 2019). In a study of analyzed film recordings of neurologists delivering the diagnosis to patients, interactional difficulties were clear – with uncertainty on the doctors’ part most evident in conversations about psychological aspects to diagnosis and treatment: Husband: “So, so, so, so, so what are you saying, she’s, she’s mentally ill then?” Doctor: “((1 second)) No, I’m saying non-epileptic attacks are um.” Husband: “Oh it, it’s the way you’re putting it across, it’s, it’s the way you’re saying it...” Doctor: “... Yeah, can I just, can I just try to ex, that, that’s, you’re not wrong, er but um, I just want to clarify what I, what I mean. Um, you know, I’m, I’m a bit worried that, that um you’re going to think that um ((0.5 seconds)) I’m thinking this is mental, you know, rather than physical. I just want to make sure that you understand that I don’t think, think that there’s a difference between those two.” (Robson & Lian, 2016).

4.3.9.2. Subtheme 7b: Lack of transparency. the problem we have as physios is often that consultants aren’t honest with patients about their true

diagnosis which makes our treatment and explanation of symptoms more difficult. - Physiotherapist, UK, (Edwards et al., 2012b).

There was a lack of transparency around the diagnosis, with the diagnosing HCP seemingly reluctant/unable to be clear and confident at communicating it. One report noted how neurologists actually “*adapted their diagnoses*” which imposed “*limits on truth telling*” (Kanaan, Armstrong and Wessely, 2009b). In a survey of epileptologists’ communication practices ($n = 125$); it was noted how HCPs typically do not introduce the differential of FND and the implications/management of this until very late in the diagnostic process – which is likely to contribute to a poor therapeutic alliance and further stigmatisation (Dworetzky, 2015). A study of HCPs in Namibia openly discussed their professional frustrations around the lack of clear transparent diagnosis, describing it as the “*hardest part ... the doctor doesn’t understand what’s wrong with them and doesn’t communicate it to them*” (du Toit & Pretorius, 2017).

HCPs providing downstream therapy indicated that patients were often unaware of their diagnosis when they came to therapy, which hindered the therapeutic relationship; with one study of speech and language therapists describing “*treading on eggshells*” and “*tentative for fear of saying the wrong thing*” (Barnett et al., 2022). Physiotherapists reported similar issues (Edwards et al., 2012b), and similarly for psychological therapy “*these people have been given a diagnosis at some point and then just sat and waited and not have any further input, which is really difficult. But the most consistent message I’m getting from people is that they don’t really understand the disorder, they haven’t been given clear information and that it’s all in their head and that’s why they’re going to psychology or even that they’re coming in expecting medication.*” (O’Connor & Reuber, 2021).

A further problem with poor communication of diagnosis, it resulted in patients not being able to communicate clearly what their diagnosis was to others, further threatening the credibility and veracity of their experience; “*even though I knew that what was happening to me was real, I still worried that because I couldn’t explain why it happened and what it was, that people wouldn’t believe me*” (Bazydlo & Eccles, 2022).

4.3.9.3. Subtheme 7c) Terminology. *It’s hard to stay on top of it for a professional, never mind a service user or patient or a client, there’s a whole mess of language.* - Healthcare provider of psychological therapy, UK (O’Connor & Reuber, 2021).

The importance of inconsistent and harmful terminology in relation to stigma has been outlined above. We reviewed further studies of terminology (Asadi-Pooya et al., 2023; Loewenburger et al., 2020, 2021) that have been undertaken following on from reviews previously carried out on this topic (Asadi-Pooya et al., 2020c; Ding & Kanaan, 2017). Loewenburger et al., (2020) surveyed a healthy population of 87 adults, who ranked their right preferred terms; with functional non-epileptic attacks (FNEA) ranked the highest preferred term, followed by dissociative seizures and functional seizures. Pseudoseizures, conversion disorder, and hysteria were the three least preferred terms which were also the most offensive. The terms pseudoseizures, dissociative seizures, psychogenic seizures, and hysteria linked most with expectations of non-recovery from psychological treatment. In a mixed method study exploring this issue (Loewenburger, Davies, Agrawal, Poole, & Cope, 2021), 39 patients reported non epileptic attack disorder (NEAD) as the most preferred term, with functional non epileptic attacks (FNEA), functional seizures and dissociative seizures following. Pseudoseizures and hysteria were the least preferred terms. A thematic analysis of 13 respondents indicated the importance of a shared acceptance and understanding between patients and HCPs, and following this the authors proposed the term “functional seizures” or “functional non epileptic attacks” to be adopted (Loewenburger et al., 2021).

A recent survey by Asadi-Pooya et al., (2023) examining the views of 1003 neurologists and psychiatrists (36% were from the Middle East and 17% were from Europe), indicated that both neurologists and psychiatrists identified “seizures” as their preferred term, with the preferred

modifiers for “seizures” being “psychogenic” followed by “functional” by both groups, with the authors outlining concerns about preferred terminology promoting dualism. A recent survey of neurologists based in Italy examining general opinions and knowledge (terminology not the primary investigation) showed the preferred term when communicating with patients was FND (Tinazzi et al., 2021a).

HCPs still use a range of terms; in one study 75% of UK GPs readily used the term “pseudoseizure” (Yogajarah et al., 2018); while an Italian study of GPs showed that functional neurological disorder was the preferred term (Marotta et al., 2021). In an Iranian study of psychiatrists and neurologists, 65% (45) of physicians favoured psychogenic non-epileptic seizures (Dastgheib et al., 2020). Thematic studies reflected the challenges around the inconsistency in terms used within their multi-disciplinary teams and called for a consistency in terminology (Barnett et al., 2022; O’Connor & Reuber, 2021). Patients outlined the importance of getting a term at all; “getting a “name” was important; it made participants feel like they have “got one over on it” (Rawlings, Brown, Stone, & Reuber, 2017). *‘I have got something wrong with me medically... I’ve got a name for it now, so I know that it’s not in my mind, it’s not all me... it wasn’t me going mad thinking I’m going crackers’* (Dosanjh et al., 2020).

It was interesting to note in a study by Hutchinson et al., (2021) – out of 75 medical students who had completed neurology placement, 21 students (28%) thought that functional symptoms described a general inability to carry out normal tasks, an impairment of day-to-day functioning.

4.3.9.4. Subtheme 7d) Intradisciplinary/Interdisciplinary/Interagency communication. *We must ascertain that everyone in the team respects the diagnosis. It is the only way to convince patients that this is the right diagnosis. [...] It is the main feature for establishing the trust that is required for fruitful rehabilitation and ‘good’ collaboration in the interdisciplinary team.* -Physiotherapist, Iceland (Klinke et al., 2019).

The theme of poor communication persisted outside the patient/HCP interaction, cascading within teams, between disciplines and between agencies, leading ultimately to poor treatment of patients with FND. There was a clear distinction outlined here between the information sharing in FND compared with epilepsy for example, the latter which has clearer protocols and shared understanding – as one study reported (Terry & Trott, 2019).

A Namibian study of HCP indicated how patient management was commonly compromised due to inadequate communication and coordination between disciplines; “*one specialist listens to the one thing and the other one does exactly the opposite thing*” (du Toit & Pretorius, 2017). The lack of a “united approach” and “consistent message” between disciplines was highlighted again by Fouche et al., (2019). It was noted that when FND was suspected but not yet confirmed, staff were often unclear about what they should say to the patient – the repercussions of this are highlighted well by one participant; “*I often feel like I am stuck on the sidelines. When I am working evening- or nightshifts and a patient asks me about the symptoms. Frankly, I do not know how I should respond, because I have no idea what has been said or if the diagnosis has been confirmed*” (Klinke et al., 2019).

Poorly joined up services and inter-disciplinary collaboration are not unique to FND, but are likely related to a chronic apathy and disinterest in the relevant stakeholders in providing care for these patients. Such reluctance may be in part due to feeling unskilled in treating patients with FND, or a dislike of a perceived stereotype. “*One participant reported that their team as a whole has FND as an exclusion criterion, citing lack of resources and specialist skills as the reason. Two participants, who regularly saw patients with FND, indicated that an important barrier was that psychologists within their team and the local mental health service would not see people with FND*” (Nicholson et al., 2021).

This inconsistency in professional communication is also displayed in the paediatric setting. McWilliams et al. (2016) describe the difficulties families experience for their children in schools due to lack of

information shared from the treating teams, leading to schools developing their own protocols to events – some of which clearly contribute to the unwanted attention and the “othering” of the child – such as evacuating classrooms or calling ambulances, despite parental wishes. This was contrasted with the distinct clarity of epilepsy protocols. A study of school nurses outlined similar concerns – “it is very difficult to have information shared so that we can actually advocate for the child...there’s minimal conversation...they don’t like to send information our way” (Terry & Trott, 2019).

Discordant views between specialties were noted – specifically neurologists and psychiatrists. Discordant opinions, while not unique to FND, likely relate to institutional issues where FND is “othered” or forgotten and may be fed by issues such as a lack of visibility in contemporary training curricula or prioritisation in research. This may fuel outdated misperceptions, and therefore lack of updated knowledge for clinicians treating FND. A study of care provided to veterans with functional seizures identified “failure of cross-disciplinary collaboration” and noted concern that mental health providers “undercut the diagnosis” by referring back to neurology (McMillan et al., 2014). This was also evident whereby both specialties differed considerably in their perspectives on feigning already described (Dent et al., 2020). A survey of 50 neurologists and 75 psychiatrists (United States) showed conflicting responses regarding diagnostic method and treatment factors– with 70% (35) of the neurologists stating video- EEG was an accurate diagnostic method most of the time, in stark contrast to 14 (18%) of the psychiatrists. The majority of neurologists – 64% (32) in this study considered that the patient’s “psychopathology” contributed to “therapeutic failure”, compared to 46% (35) psychiatrists (Harden, Burgut, & Kanner, 2003). An older study of GPs with respect to opinions of the diagnosis of functional seizures in their patients, found that eight (35%) of those polled did not agree with this diagnosis with one claiming the diagnosis was “an attempt by the neurologist to ‘pass along’ care of a refractory patient” (O’Sullivan, Sweeney, & McNamara, 2006). In a large study of electronic health records of 750 patients being worked up for functional seizures, the HCP documentation showed ambiguous language. Even when communicating a confirmed diagnosis of FND, they used equivocal phrases such as “believe to be”, “thought to be”, and “felt”, which as the authors note may have repercussions on treatment (Altalib et al., 2016). An Australian study found that out of the 82 newly diagnosed patients, 44 (54%) were not provided the diagnosis of FND, 20 (24%) did not have their diagnosis documented in their medical record, 44 (54%) were not told of the diagnosis (Petrie et al., 2023).

Studies examining official diagnostic coding in the United States revealed that FND is coded for in a minority of cases; neurologists, after diagnosing FND, selected FND-related ICD-10 codes in only 22.8% of consultations. When presented with FND and non-FND scenarios with equal levels of information, neurologists coded for FND 41% less often. The strongest predictor of noncoding was the belief that FND is a diagnosis of exclusion, the authors concluded that the impact of FND was underestimated by over fourfold (Herbet et al., 2021). Underestimating the presence of FND and its impact is related to stigma on an institutional level, given it is likely related to lack of knowledge and training about FND, discussed in further detail below.

In a study on pediatric coding of functional seizures, 17 different diagnostic ICD-10 codes were used by 61 pediatricians. Interestingly the most widely used code in this study fell under the realm of “F91.8 - Other Conduct Disorders” which is likely to have significant consequences on HCPs’ perceptions of voluntariness and validity of the seizures in children (Wichaidit, Østergaard, & Rask, 2014).

4.3.10. Theme 8. Knowledge, Training and Skillset

Institutional stigma and discrimination were highlighted by this theme, from which the following subthemes arose: a) knowledge and education, b) feeling “ill-equipped” and c) call for training.

4.3.10.1. Subtheme 8a: Knowledge and education. To be perfectly honest I had never heard of it, and when I first came in contact with the student who was having an episode, that’s what the parents always called it, an episode, I basically, to be quite honest with you, I thought she was just faking it. - School nurse, United States (Terry & Trott, 2019).

A large survey of 963 psychiatrists showed that 75% had never received training in functional seizures and 39% admitted only having a limited understanding. Those who received training were more interested and had a better understanding of the disorder –performing better on questions about theoretical knowledge (Aatti et al., 2016). In a survey of neuroscience nurses’ attitudes ($n = 68$), 75% (51) agreed their knowledge of FND was limited, with 85% (58) reporting they received inadequate education around FND during training, with less perceived training correlating with negative attitudes (Ahern et al., 2009). In a study of 702 physiotherapists’ knowledge of ten neurological conditions, the majority ranked their knowledge of functional disorders between the seventh and tenth they felt most knowledgeable about (Edwards et al., 2012b). Lack of physician knowledge and training was seen as a barrier to managing patients with FMD by 32% (total $n = 864$) of members of the Movement Disorder Society, more so by respondents in non-US countries (LaFaver et al., 2020). A Nigerian study of pediatric doctors (174) examining knowledge of “conversion disorder” revealed that only 2.9% (5) displayed good knowledge, the majority answering questions incorrectly (Ndokuba et al., 2015). A study of HCPs in Egypt found that less than half thought they had a good knowledge of FND, with most of them concerned about missing an “organic disorder” (Alamrawy et al., 2023).

Few studies reported on formal teaching programs, with one US report showing the majority of programs did not provide a curriculum for training regarding communicating the diagnosis or evidence-based treatment for FND. In this study, 18% of neurology residents reported not learning how to communicate the diagnosis and 77% responded that they were not taught about treatment (Milligan et al., 2022). A study of 324 medical students and early clinicians based in Iraq showed that 56% reported that they received no teaching about FND, while 28.4% reported receiving <1 h of teaching, males reported more teaching hours than females, with a positive correlation between teaching hours and confidence in managing FND (Al-Sibaheeh et al., 2023). A recent sample of 75 UK medical students – the majority ($n = 50$; 66.7%) considered the teaching they had received on FND during their medical training was insufficient, with 23 (31%) stating it was not covered at all (Hutchinson et al., 2021). In a study examining feedback of experts who teach about functional seizures, almost 50% reported that part of the teaching focusses on the “wasted resources” associated with this disorder – likely conveying the implication that patients too, are a waste of time (Dworetzky, 2015).

Qualitative reports outlined the difficulties HCPs have with patients without proper training – “Participants ‘utilized trial and error and felt like it was guesswork’ – leading to feelings of confusion and helplessness (Barnett et al., 2022). Similar sentiments were expressed by OTs– with lack of education cited as a barrier to treatment (Nicholson et al., 2021). HCPs in Namibia outlined how lack of knowledge and ignorance by professionals contributed to misdiagnosis, unacceptance and stigmatisation, and called for urgent public education to de-stigmatize the disorder (du Toit & Pretorius, 2017). School nurses reported that the inadequate education during nursing training contributed to misperceptions around malingering. This sample commented they were not able to find information via their usual resource banks and had to rely on children’s families for information which was often nonexistent (Terry & Trott, 2019). One recent study of emergency care providers (50 physicians and 10 advanced care providers) found 95% ($n = 57$) reported a lack of understanding about FND (Yu et al., 2023). This lack of professional knowledge seemed to perpetuate a sense of the patient being disbelieved, and having to impart their own knowledge to professionals engendered a sense of being “othered” (Staton et al., 2023).

4.3.10.2. *Subtheme 8b: "Ill-equipped" - lack of comfort, confidence. Well, I don't feel competent or skilled. I just look and I think, "Oh, god, how am I going to get through this one?" - Occupational Therapist, UK (Nicholson et al., 2021).*

A survey of 360 HCPs (mainly neurologists) from 17 Latin American countries showed under half (49.5%) considered that they feel confident in their ability to diagnose functional seizures (Ladino et al., 2021). In a study of physiotherapists (702), only 25% agreed that they were well supported by their relevant neurologist, 18% worried they might be making the patient worse (Edwards et al., 2012b). Another study of opinions of 115 various HCPs managing functional seizures revealed the following; on a scale of 0–10, neurology responders expressed highest confidence (mean 7.7) followed by nurses (7.2) and primary care HCPs (4.3) (Sahaya et al., 2012). On a scale of 1–10, the mean confidence level of GPs with respect to the condition functional seizures was 5.7. (O'Sullivan et al., 2006). Another study of 120 GPs examining attitudes to functional seizures reported that 48% felt a lack of confidence in dealing with patients, with younger GPs less confident than older GPs (Yogajarah et al., 2018).

Reports showed that lack of confidence was compounded by perceived lack of supportive expertise; *"There's this pocket of patients that I can't, I don't have the skills I can't help I felt quite unsupported, like I didn't really know where to, you know...there was no kind of clear pathway or no clear resources which I could use"* (Barnett et al., 2022). Lack of confidence and uncertainty meant HCPs were sometimes not willing to work with patients with FND at all (Jordan et al., 2019). Patients picked up on this lack of comfort, which is likely to have further contributed to sense of being "othered"; *"I've found that ... more absolute terror on the faces of people who didn't know what to do with me. In hindsight, I think some of it was just complete uncertainty about what to do with this [FND]. Just complete lack of awareness of the condition to what to do with someone with it"* (Staton et al., 2023).

4.3.10.3. *Subtheme 8c: Call for more training. Younger team members often knew nothing about FND prior to starting working in neurology because FND was not covered in their schools' curricula. However, these team members found that "[FND] is no less important than the organic neurological disorders. It should even be granted more attention because FND patients more frequently receive too little comprehension of their situation, even from healthcare professionals."* - Healthcare professional (Klinke et al., 2019).

An Iranian survey of neurologists showed that 90% endorsed a need to attend teaching about functional seizures to improve practice (Asadi-Pooya, 2016). In a sample of 133 GPs, 89% expressed a need for more access to information or taking part in professional courses (81%). Another survey of 68 mixed therapy providers revealed less than half (48%) felt comfortable treating FND and a vast majority (84% of physicians and 90% of non-physicians) agreed or strongly agreed that more training would increase their comfort (Taplinger et al., 2020). A recent study of 568 mixed HCP (neurologists, psychiatrists and rehabilitation specialists) regarding specialist residency training found that 45.5% of participants responded they never received any teaching on FND. In this study the vast majority (87.9%) stated they were not trained sufficiently in FND and 85.3% stated they did not have sufficient knowledge (de Liege et al., 2022). Yu et al., (2023) surveyed 60 emergency care staff – just one respondent answered they were familiar with FND resources and 79% ($n = 47$) stated endorsed a need for education around FND. A study of Namibian HCPs outlined the need for better education and training – that was simply not available there at all "you have to go out of the country for training" (du Toit & Pretorius, 2017). Dworetzky (2015) outlines the lack of standardized formal educational curriculum in USA neurology residency training, calling for a more updated approach.

There was a positive correlation between the number of patients under the current care of respondents and their confidence about

treating functional seizures (Hingray et al., 2017); and seeing more patients per year was significantly correlated with greater confidence and knowledge in diagnosis and discussions around treatment (Lehn et al., 2019). Physicians who had received at least one specific teaching course on functional seizures significantly more often believed themselves to have a better understanding and obtained better results for the questions on theoretical knowledge (Aatti et al., 2016).

4.3.11. Theme 9. Care – access and inconsistencies

Institutional stigma and discrimination (often unintended) were highlighted by the theme access to care and inconsistencies in care. The following subthemes were found here; a) stigma as barrier to treatment, b) lack of available expertise and c) call for services and standardized treatment guidelines.

4.3.11.1. *Subtheme 9a: Stigma as barrier to treatment. Five providers commented on the challenges that patients face because of societal stigma and prejudice, because "society knows nothing about this, which is the huge problem, and automatically people are assumed to be malingering" - Healthcare professional, South Africa, (Fouché et al., 2019).*

From the HCP perspective, in a survey of 62 mainly epileptologists, stigma regarding functional seizures was perceived as a barrier to treatment in 29.5% of respondents (Carter et al., 2018). In a survey of HCPs from 63 countries, "stigma/lack of awareness" was identified as a barrier to the diagnosis and treatment for functional seizures in 70% of countries (Hingray et al., 2017). In a large Latin American study ($n = 360$) stigma was identified as a barrier to diagnosis and treatment by 42% (Ladino et al., 2021). From a patient perspective, it has been discussed how patients reported that stigma around the diagnosis stopped them from accessing treatment – mainly due to concerns about entanglement with a mental health diagnosis and lack of awareness or being judged (Lakhani et al., 2022). Furthermore, anticipated stigma or fear of judgement or disbelief from HCP seemed to be a barrier to some patients disclosing information; *"I feel like I was gonna be in that situation again where I couldn't really say what I wanted to because it's almost feeling like you might be judged in a certain way"* (Staton et al., 2023).

4.3.11.2. *9b) Lack of available clinical expertise. My consults have been rejected, pushed to the side or referred to some other service like memory service, geriatrics, or memory clinic. We do not really have a good way of addressing this patient. We are basically left in limbo.* - Neurologist, United States (McMillan et al., 2014).

Lack of available expertise manifested as either an existing lack of services for patients or sometimes a rejection of referrals due to perceived lack of resources/skillset. A study of HCPs from 92 countries revealed that 48% of respondents indicated that missing availability of referral services was one of the factors considered as 'often' or 'always' limiting the management of patients (La Faver et al., 2020). In a survey of 130 neurologists, only 35% of respondents replied that they were able to refer "all" of their patients for psychological treatment (Mayor et al., 2011). In a survey of 62 mainly epileptologists, 34% reported lack of psychological treatment services was a significant barrier to treatment; and less than half stated patients received psychotherapeutic assessment (49%) or neuropsychological testing (41%), despite higher referral rates (Carter et al., 2018).

Psychological treatments were the biggest hurdle reported in many studies. In a survey of HCP from 63 countries, psychological treatment was one of the most commonly identified barriers to the diagnosis and treatment for functional seizures, with large discrepancies in low to middle and high -income countries, being very scarce in low-income countries (Hingray et al., 2017). In Latin America lack of accessible HCP who know about functional seizures was cited as a barrier in 45% (Ladino et al., 2021) and similarly by 40.5% in a Chinese study (Tong et al., 2018). A Brazilian study showed that out of 11 epilepsy centers, treating epilepsy and functional seizures, psychotherapy was not "easily

obtained” available in nine centres (Valente et al., 2017b). Some doctors reported that they had to make do with their own “makeshift” psychological treatment in the absence of available services (Hutchinson et al., 2021).

Lack of services are not unique to FND. However, it is clear from our findings that there is a clear disparity with services for FND compared with other neurological disorders (Cuoco et al., 2022; O’Keefe et al., 2021), indicating this patient group are potentially being treated differently on the basis of their FND diagnosis. When viewed alongside other findings such as the discomfort and reluctance to manage this group (theme 8b) it is probable that there is likely an extra layer to this dearth of services beyond the usual limited resources, that is related to institutional disinterest and stigmatizing attitudes towards a perceived stereotype. Barnett et al., (2022) discuss how referral to community SLT teams was not possible because they would only accept patients with stroke, and how long waiting times for psychology services hampered management of patients. Patients reported being told they couldn’t be seen by specialist clinicians because of the label of their functional motor disorder (Zeun & Hunter, 2023). Psychiatrists found that referrals to psychology services were often rejected by community services and psychology services (Jordan et al., 2019). This was also found in a study of OTs, with participants stating that psychologists within their team and the local mental health service would not see people with FND – and even FND as a whole was an “exclusion criterion” (Nicholson et al., 2021).

4.3.11.3. Subtheme 9c) Call for services/Standardized treatment guidelines. Say if you were in a new in the area of, um, head and neck cancer, you might be able to go on like the [RCSLT] website for some support [but for FND] there’s nothing. Even if you went on to the royal college or specific to speech therapy there’s kind of minimal, um, guidelines or evidence base out there, so that that makes it tricky. - Speech and Language Therapist (Barnett et al., 2022).

Over 75% of 120 GPs expressed a need for a dedicated diagnostic and management service for functional seizures (Yogajarah et al., 2018). In a survey of 130 UK-based neurologists - >95% of respondents endorsed the need for the development of evidence-based management pathways, and 75% of respondents thought that such pathways were likely to reduce healthcare costs (Mayor et al., 2011). A large study of Chinese HCPs (n = 434), 47.2% stated that the ability to manage patients was (‘often’ or ‘always’) restricted by lack of treatment guidelines (Xie et al., 2021).

A survey of 66 HCPs working in pediatrics showed that 66% thought their local service managed these young people with functional seizures “very poorly” and six months after diagnosis nearly 20% of patients were still taking dangerous anti-epileptic medications, despite not having epilepsy. This group highlighted the preference of joint psychiatry and neurology services and the importance of liaison with schools (McWilliams et al., 2017). In another pediatric study of 61 Danish HCPs, 78% highlighted the need for clinical guidelines, with only 13% rating the existing treatment services as sufficient. While 62% of this sample believed that collaborative care involving different specialties was the ideal model for management of children diagnosed with functional seizures, only 23% reported “often” referring to Children and Adolescent Mental Health Services (CAMHS) in diagnosis, suggesting a discrepancy between ideal treatment and what gets offered (Nielsen et al., 2018). Generating a database of psychologists who specialize in the treatment of FND was raised as necessary (Fouché et al., 2019). Numerous qualitative studies highlighted the need for a cohesive MDT approach to management – with clear simple clinical guidelines, particularly for patients outside major centres (Barnett et al., 2022; Fouché et al., 2019; McMillan et al., 2014).

4.3.12. Question 3. What helps to reduce stigma in FND?

4.3.12.1. Theme 10. Anti-stigma. This theme will be divided into anti-stigma interventions and general anti-stigma themes that were found from our search. The definition of an anti-stigma intervention is quite broad – and has been defined as an intervention with the aim to reduce negative attitudes and beliefs associated with a condition, which can occur at multiple levels; for example, education interventions presenting factual information about the condition with the goal of correcting misinformation or contradicting negative attitudes and beliefs (National Academies of Sciences, 2016). Interventions that aim at changing characteristics of the individual such as knowledge, attitudes, behavior, self-concept, self-esteem, coping skills, and empowerment are defined as “intrapersonal stigma interventions” (Heijnders & Van Der Meij, 2006), and also constitute some of our findings in this section, in addition to educational interventions (Cope et al., 2021; Gurcan et al., 2022; Hall-patch et al., 2010; Medina et al., 2021; Pohlmann-Eden et al., 2019; Thompson et al., 2005).

4.3.12.2. Subtheme 10 a: Anti-stigma interventions. Learners rated significantly more favorable attitudes towards patients with FND; in particular, being more likely to report that patients with functional symptoms are truthful about their symptoms (75% vs 95%, p < 0.001), and less likely to believe that they were being manipulative (48% vs 80%, p < 0.001) (Medina et al., 2021).

Cope et al., (2021) carried out a single education session, aimed patients with FND and their relatives (193 patients and 153 relatives), facilitated by professionals to enhance patients’ and relatives’ understanding and acceptance of diagnosis. They found significant increases in post session ratings of understanding of diagnosis, belief in treatability, hopefulness regarding recovery and agreement with diagnosis, in keeping with intrapersonal aspects of stigma reduction, in addition to increasing factual information (Cope et al., 2021). Gurcan et al., (2022) designed and delivered a three-hour psychoeducation group aimed at improving knowledge about functional seizures, measuring perceptions with the Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006).

Post-intervention, young people reported increased knowledge of functional seizures and ability to cope with the condition which was maintained at 6-week follow-up. Also in this study, there was a significant decrease in Emergency Department visits in the psychoeducation group. Furthermore, young people felt significantly more confident in explaining functional seizures to others, which is an important finding in keeping with themes of legitimacy and explanations, as outlined by Karterud et al., (2016).

Other studies focused more explicitly on HCP communication (Hall-Patch et al., 2010; Pohlmann-Eden et al., 2019; Thompson et al., 2005). Hall-Patch et al., (2010) designed a communication procedure consisting of a patient information leaflet and a communication strategy for neurologists which was assessed for acceptability and effectiveness in a sample of 50 patients with functional seizures recruited at point of diagnosis. Follow up revealed 94% of those who remembered the booklet found it clear and easy to understand; that 94% of patients stated that they had their questions answered by the neurologist, 90% of patients felt they had been “listened to,” and only 14% of patients found the consultation confusing. Patients volunteered more negative than positive feelings initially, with prompting, positive feelings were reported more frequently than negative sentiments. After 3 months, 14% of patients were seizure-free and 63% reported a > 50% reduction in seizure frequency.

Thompson et al., (2005) designed a 6-step protocol for patients with functional seizures to administer post diagnosis. The protocol involved explaining the diagnosis and suggesting psychotherapy and instilling hope for recovery. Stigma emerged as a common theme in discussions and part of the intervention involved reframing patient’s beliefs around

their diagnosis...“Some patients’ families had implied for years that the patients were standard in many ways”. They contacted 48 patients after two years, outcomes included engagement with psychotherapy and changes in seizures. Of those 48 patients, 100% attended between one to eight psychotherapy sessions. Twenty-four patients (50%) reported that their seizures were gone 2 years post-diagnosis and of the remaining 24 patients only five reported no change (Thompson et al., 2005). Pohlmann-Eden et al. (2019) Designed a communication tool for patients with “psychogenic nonepileptic seizures” “1 pager PNES “ which focussed on education and empowerment for patients. This was tested with small focus group- of seven patients with positive results. All participants expressed high satisfaction and it rated highly on diagnostic and treatment domains - the authors concluded this tool empowered patients from the beginning of their diagnosis (Pohlmann-Eden et al., 2019).

Medina et al., (2021), explored comfort level and perceptions of FND in clinicians, designing workshops for HCPs (psychiatrists and neurologists, total 47). Post workshop questionnaires revealed participants exhibited a clearer understanding of FND, greater comfort level with need for investigations and discussing diagnosis, and a clearer understanding of treatment. They also demonstrated significantly more favorable attitudes towards patients with FND; in particular, being more likely to report that patients with functional symptoms are truthful about their symptoms and less likely to believe that they were being manipulative. Results from the post-test showed that nearly all of the participants were able to appreciate that functional symptoms are “real”, that treatment can help control, and believe that FND patients deserve the same level of care as those with other neurological diseases (Medina et al., 2021).

4.3.12.3. *Subtheme 10b: Shared understanding. So you try and reposition their understanding in a way that makes them feel validated and heard, and empathize with a sense of uncertainty that they’re feeling and not knowing – Healthcare professional, South Africa, (Fouché et al., 2019).*

Several studies emphasized the importance of validation, respect and empathy in patient communication (Fouché et al., 2019; Klinko et al., 2019; McMillan et al., 2014; O’Connor & Reuber, 2021; Pretorius & Sparrow, 2015). Klinko et al. (2019) carried out focus group interviews of HCPs to explore facilitating and inhibiting factors in the care of patients with FND identifying two main categories during discussions; “giving the diagnosis to patients – a moment of fragility and opportunities” and “organization of care – ensuring the continuity and protecting patients’ self-image”. Another study focused on the perceived certainty with which the neurologist delivered the diagnosis – which was integral to the patient’s own appraisal of the condition (Thompson et al., 2009). In a study of adolescents, the idea of functional seizures as a “legitimate disease” contributed towards better participation in social activities (Karterud et al., 2016).

The importance of interdisciplinary collaboration was highlighted; *[The physiotherapist] listened to what the psychologists had to say... it was really crucial I guess, that they worked together, the psychologists couldn’t have done that work with me like that, and the physio couldn’t have [done the psychological work]. Yeah, it would, would have been like patching something up without actually getting to the root of the problem so yeah so working together it has just been really effective (Zeun & Hunter, 2023).* Patients described the importance of using individually tailored explanations and language that made sense and was meaningful for the individual, particularly when discussing more emotional elements, in a way that was not alienating (O’Connor & Reuber, 2021; Staton et al., 2023). In one study examining the views of patients and doctors, the interpersonal aspects of the explanation process such as reassuring, validating and spending enough time, were seen as more important than the physiological disease explanation (Hutchinson et al., 2021). One of most important factors for coping with the diagnosis, was being taken seriously by the health provider (Dosanjh et al., 2020; Karterud et al., 2010).

5. Discussion

Stigma in FND is not new. For centuries, patients with FND have been subject to discrimination and ridicule but now the tide is changing, with a surge of interest and research around FND in the last 20 years. However, there are gaps in the stigma literature and scope for further studies and interventions to help prevent or combat stigma.

Our review included studies spanning 148 countries, encompassing a broad range of geopolitical regions and cultures, involving 18,886 participants. Of these, 4889 were patients, 13,123 were healthcare professionals, and 526 were caregivers. Our themes showed how stigma occurs as a multifactorial and layered process, with inter-related intrapersonal, interpersonal and structural aspects. From a quantitative viewpoint, our review found that stigma has mainly been studied in functional seizures. While there are few control studies, we found that stigmatisation was over 40% more likely to be experienced by patients with FND compared to patients with epilepsy – the latter itself a highly stigmatized condition (Kwon et al., 2022). For patients with functional seizures, stigma is associated with poorer quality of life and lower perception of self-control. Stigma has implications for caregivers, with higher caregiver stigma associated with patient and caregiver anxiety, and caregiver burden. Few studies examined the perspective of the public or online community. We identified six anti-stigma interventions, that were mainly in the domains of education and patient empowerment.

Our themes and subthemes demonstrate how stigma in FND can be considered a dynamic and organic process (Fig. 3). The ‘roots’ of stigma could potentially be considered to originate in the systemic lack of interest in FND on a structural level, impacted by historical societal attitudes, and dualistic beliefs about functional symptoms. This is likely driven further by an ingrained belief among service managers and providers that FND is fundamentally ‘less’ than other conditions. Resulting organisational deficits might lead to an apathy around training, and development of services and care pathways – driving perceptions that FND “not a priority”. This lack of visibility, priority and cohesiveness in training and services likely perpetuate the myth that FND isn’t real or that it is “non-deserving of care”. From an interpersonal stance, these structural deficits and outdated misperceptions about FND

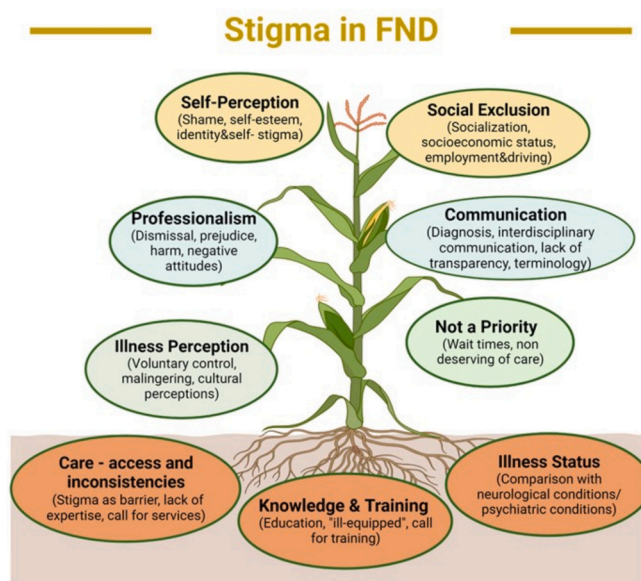


Fig. 3. Themes and subthemes related to stigma in FND. Stigma occurs as a dynamic and organic process, the results of which can manifest in shame, harmful interactions and social exclusion. These are rooted in the lack of knowledge, training and care pathways for FND, and further impacted by historical dualistic attitudes about mind and body (BioRender.com).

– such that individuals can voluntarily control their symptoms or even worse are malingering – are likely to lead to healthcare dismissal, prejudice and harm. Further, as our review shows, the lack of prioritisation in training and services leads to HCPs feeling incompetent and unskilled during therapy provision. These feelings, combined with a lack of transparent interdisciplinary communication and collaboration may engender clinician helplessness, which perhaps leads to patient blame. From the perspective of the individual with FND, the ‘fruit’ of these problems may manifest as intrapersonal difficulties, such as shame and low self-esteem, and impact on an individual’s sense of identity and self. This may result in a social exclusion and lack of treatment seeking for troubling symptoms, perpetuating a negative stigma cycle. In many ways our review findings align with recognised stigma theories and healthcare – such that stigma influences several processes including availability of resources, social relationships, and psychological and behavioural responses, that ultimately may lead to adverse health outcomes (Hatzenbuehler, 2016; Hatzenbuehler, Phelan, & Link, 2013).

5.1. Comparison with previous literature

Our review demonstrates some similarities with previous reviews on this topic, such as HCP stigma, impact of stigma on the patient, impact of terminology, and lack of knowledge and training (Annandale et al., 2022; Foley et al., 2022; Rawlings & Reuber, 2016, 2018), which have been described in the introduction. We also found similar themes regarding professionalism – demonstrating that attitudes of dismissal and disinterest are very much still present. The theme of self-stigma manifests as a prominent finding, in keeping with previous literature, and is likely impacted by perceived prejudice from others (Corrigan & Rao, 2012). In addition to these similarities, the present review also provides some further insights into how stigma processes unfold in FND.

Firstly, with regards to population, we included individuals with functional neurological symptoms of any sub-type, as opposed to just functional seizures, the dominant FND subtype in previous pertinent reviews on this topic (Annandale et al., 2022; Rawlings & Reuber, 2016, 2018). Foley et al., (2022) included other functional neurological symptoms in their qualitative synthesis of stigma experiences in FND, however out of the 16 papers included in their review, 13 focussed on functional seizures. Our review found that self-stigma, prejudice and discrimination exist across a range of FND phenotypes, including tremor, weakness, gait problems, and speech and language symptoms.

Furthermore, there have been several studies carried since the time of these previous reviews that further inform stigma processes for this group. For example, Peacock et al., (2023) incorporate a sociological viewpoint of the “*medicalization*” of symptoms and how it informs legitimacy of the symptom experience in functional seizures. Other recent studies explore the individual’s experiences of specific services such as physiotherapy (Zeun & Hunter, 2023) or psychological services (Staton et al., 2023) - areas which have not been explored much in previous literature. Studies from India and Argentina add further knowledge into how different cultural contexts can shape an individual’s experiences of care (Lakhani et al., 2022; Maria Marta et al., 2023).

In addition to the perspectives of individuals with a diagnosis of FND, we ensured a focus on HCPs and the general public in this review. In doing so, we were able to build a depiction of the inter-related facets of stigma and how different domains influence each other. Taking one example of this, a recent study examining perceptions of emergency care physicians (a group, to our knowledge, not evaluated before exclusively in their own right), showed significant knowledge deficits of FND (Yu et al., 2023). Subjective patient perceptions of dismissal in the emergency setting are particularly extreme, as outlined previously (Karterud et al., 2010; Robson & Lian, 2017) – demonstrating how a lack of professional knowledge in this group may translate onto negative experiences for individuals seeking help. Recent additional studies of HCPs carried out in Iraq (Al-Sibahee et al., 2023), Egypt (Alamrawy et al.,

2023) and internationally (Asadi-Pooya et al., 2023) add further perspectives into stigma processes as they occur in regions which have not been represented much previously in the existing literature (Annandale et al., 2022; Rawlings & Reuber, 2018).

Furthermore, on the topic of HCP – previous reviews of HCP incorporate, for the most part, the views of physicians and hospital nurses (Rawlings & Reuber, 2018). The present review incorporates the views of many disciplines outside these, such as speech and language therapists (Barnett et al., 2022); school nurses (Terry & Trott, 2019), occupational therapists (Nicholson et al., 2021) and psychologists (O’Connor & Reuber, 2021). Incorporating this data, we found similar themes to those that exist previously, but also other findings, such as lack of interdisciplinary/ inter-agency communication, the effects of lack of transparency in the diagnostic process, and feelings of incompetency among therapists – and again these reported the views of clinicians treating the fuller spectrum of FND symptoms outside functional seizures. Further studies, such as that by Begley et al. (2023) also shed light onto how the legitimacy problems experienced by patients may translate to them receiving poor care - where attitudes regarding illegitimacy affected referral to physiotherapy among medical doctors (Begley et al., 2023). The numerous larger scaler studies of HCPs across diverse regions, show how, structurally, lack of access to services and treatment guidelines influences care, and that HCPs are calling for change (Fouché et al., 2019; LaFrance et al., 2012; Xie et al., 2021; Yogarajah et al., 2018).

Our study shows some further novel findings in the area of communication and teaching. While the area of clinical communication has been outlined as problematic previously (Annandale et al., 2022), the findings from the present study show that in addition to the interpersonal communication (usually the diagnostic consultation) being problematic, communication issues crop up elsewhere, that are structural in nature. For example, a Danish study showed the inaccurate coding for FND as Conduct Disorder in children (Wichaidit et al., 2014), and studies from the USA and Australia showed how FND is often not documented in the medical record (Petrie et al., 2023) or not officially coded for at all (Herbert et al., 2021). This likely adds to the invisibility of FND – propelling further neglect, and maintaining the harmful notion that it is a condition not worthy of treatment and research. This invisibility is again present in the lack of prioritisation of FND in medical curricula (Al-Sibahee et al., 2023; de Liège et al., 2022; Milligan et al., 2022), further perpetuating the idea that FND is unimportant and not worthy of attention.

Our review showed findings in the area of social media and general public perceptions, which have implications in how to move forward with counter-stigma interventions for this group. In addition to the study by Popkirov et al. (2019) which was included in the review by Annandale et al. (2022), we included articles reporting on how FND is discussed in social media, which showed offensive material by (self-declared) professionals towards patients (Myers et al., 2016), and further studies examining media and general public perceptions (Carruthers et al., 2021; Coey et al., 2023). Though there are few studies in this domain, this material is helpful as cultural perceptions and online material are likely to influence patients and carers as they interact about their illness online, and may inform future anti-stigma material.

Lastly, we also included anti-stigma interventions in our review. The review by Annandale et al. (2022) included some material relating to protective factors against stigmatizing experiences in functional seizures. However, the present review is the first to our knowledge, that collated evidence on specific interventions that may help combat misperceptions and drive patient empowerment – and while these are of modest number, provide a useful platform in considering how future anti-stigma interventions can be developed.

5.2. Perceptions driving stigma

The origins of the stigma in FND are complex and a full analysis is

beyond the scope of this paper, but some are likely to stem from historical and contemporary sex and gender-based issues around “hysteria” and related conditions (McLoughlin et al., 2023). The present review showed that dualistic health beliefs, perceptions around voluntary control and internalised shame influence stigmatizing interactions.

A key theme highlighted in this review, was the discomfort of any association with the “psychological”, “psychiatric or” mental” – propelled by dichotomous “mind versus body” perceptions. Complicating this, is the high degree of psychiatric comorbidity in patients with FND (Carle-Toulemonde et al., 2023) – for which many will undoubtedly suffer stigma already. For patients, there is often a struggle grappling with severe symptoms on a background of normal biomarkers. For many, this just simply does not make sense with their level of debilitation, and once HCPs see normal scans are more likely to dismiss “... doctor in the hospital said that because there were no abnormalities in my brain waves that it could be nothing else but voluntary” (Robson & Lian, 2017). There is some evidence of biomarkers for FND in the literature – such as increased connectivity between motor control and emotional processing areas in brains of individuals with FND (Bègue et al., 2019; Perez, Edwards, et al., 2021; Perez, Nicholson, et al., 2021). Weber et al. (2022) evaluated resting-state functional connectivity in a multi-centre sample of 86 FND patients and 86 healthy controls, finding that patients with FND could be reliably distinguished from healthy controls (accuracy of 72%), based on this experimental method. However, it is important to point out that “over biologizing” is not likely to help stigma, as it may be seen to be an attempt to negate the psychological, and still contributes to the “othering” of the individual with the condition.

As long as “psychological issues” are viewed negatively or dualistically, it is likely FND will be viewed in tandem this way. FND is a neuropsychiatric disorder – conceptualised as a disturbance in areas involved in cognitive, emotional, interoceptive and motor domains (Aybek & Perez, 2022); and so, it is not justifiable to gloss over the psychological processes in the brain that contribute to etiology and symptoms. Moving forward from dualistic models will require persistent and sensitive transformation in cultural belief systems about mind, brain and body. That said our review found that, while some patients struggled with psychological explanations (Baxter et al., 2012; Nielsen et al., 2019) many patients tended to agree with them (Arain et al., 2016) and attended for psychological follow up (Carton et al., 2003), hopeful that psychotherapy could help find them a way forward (Baxter et al., 2012; Fairclough et al., 2014; Wyatt et al., 2014). A large survey of 1048 patients with FND found that the majority of respondents agreed that FND occurs due to a combination of physical and stress/trauma related factors (Butler et al., 2021).

There was significant data in our study showing that HCPs think many patients with FND feign seizures for attention. Though we recognise the complexity of this issue, there is clear evidence that FND does not equate to malingering (Edwards, Yogarajah, & Stone, 2023). The phenomenology of FND has remained stable and consistent across time, culture and geography. Patients improve with treatment, which would not be expected of fabricated symptoms, and moreover numerous experimental neuroimaging and neurophysiological studies provide support that FND represents underlying disturbance to brain function implicated in inhibition motor function (Cojan, Waber, Carruzzo, & Vuilleumier, 2009a, 2009b) and a sense of agency (Voon et al., 2010). A study examining covert attitudes towards sickness (an affinity for the sick role) using the implicit association test did not find support for the idea that patients with functional seizures harbor positive attitudes towards illness (Testa & Brandt, 2010).

5.3. Stigma as an interactional process

It is plausible that many HCPs do not mean to come across as invalidating and are trying to act in what they perceive to be the patient’s best interests. In a study of psychiatrists ($n = 963$), 26% felt it could be

therapeutic to confront the patient about the “false nature of their symptoms” (Aatti et al., 2016). While perhaps well-meaning, this is not only inaccurate but distressing for patients, many of whom have been through adverse life events already where they may have had to face disbelief about the reality of threatening events (Ludwig et al., 2018).

There is a strong association with FND and early adversity such as physical, emotional and sexual abuse (Hailes, Yu, Danese, & Fazel, 2019; Ludwig et al., 2018), meaning there are a proportion of patients with FND were likely raised in caregiving environments that were unpredictable and derogatory. Given how early caregiving relationships prime our template on how we see the world, it is possible that some patients might be defensive around an anticipated dismissal, or perceive neutral caregiving (including HCP) interactions as antagonistic. That said, it is clear that many HCPs do treat these patients with contempt or ignore them. Also, importantly - patterns of abuse tend to repeat – and it is notable how people who suffered physical and psychological abuse were more likely to suffer delay to diagnosis (Kerr et al., 2021; Valente, Alessi, Vincentiis, Santos and Rzezak, 2017a). For many patients, the medical setting in itself can be experienced as traumatic, and HCP interactions contribute to this (Hall & Hall, 2017). Acknowledging this, it is helpful to have an awareness of these potential dynamics and background factors, and allow time and sensitivity during consultations and therapy sessions.

In this vein, there is an important role for clinicians within the multi-disciplinary setting, such as clinical psychologists or mental health practitioners who have expertise in this area, to educate staff about these interconnected trauma/stigma challenges, and use this knowledge to inform care. A sensitive, trauma-informed approach, with particular attention to the risk of medical traumatisation in this group is likely to pave the way for more empathetic and validating interactions. The concept of trauma-informed care while well-recognised in mental health, is also recently gaining traction in neurology (Ortiz, Gilgoff, & Burke Harris, 2022). Additionally, this knowledge can be used to develop appropriate anti-stigma interventions - a recent study has outlined how adopting a validating stance towards the patient experience is helpful in countering stigma-related challenges for patients with FND (McLoughlin, McGhie-Fraser, Carson, Olde-Hartman, & Stone, 2024).

5.4. Communication

Communication – especially HCP-patient interactions featured repeatedly as the area of major challenge; with patients feeling misunderstood and dismissed, and on the flipside, HCPs struggling with what to say for fear of not getting it right. Robson and Lian (2016) in their video recordings of consultations noted that conversations break down at two distinct points – discussions of causes of patients’ functional seizures and discussions about treatment – usually psychotherapy. Conversation analytic studies between neurologists and their patients demonstrated the intricacies and fragilities of these interactions (Monzoni, Duncan, Grünewald, & Reuber, 2011a, 2011b). It was noted that there was a “co-occurrence between patients’ resistance, and formulation effort” – formulation effort being hesitations, self-corrections and reformulations on behalf of the doctor. Though doctors’ formulation effort was sometimes provoked by resistance, this was not always the case – sometimes formulation effort was increased well before patients had shown any resistance, or even in cases where the patients “fully aligned” with the doctor. These interactional behaviours on behalf of the doctors implicate an extra layer of “delicacy”, even where none might be needed suggesting a degree of “defensiveness” or “pre-existing concern” (Monzoni et al., 2011a, 2011b). The benefits of a decent explanation can be extensive; Lagrand et al. (2023) found that patients who received a satisfactory explanation demonstrated significantly reduced health care use, whereas an unsatisfactory explanation resulted in significant additional healthcare use and associated cost.

The diagnostic point emerged as a crux from which the trajectory can be positive or negative for the patient. There seems to exist a difficult

balance between trying to deliver the diagnosis in a transparent way incorporating all the biopsychosocial components while also being upfront about causes and treatments. Tiptoeing around elements of the diagnosis is not helpful - patients clearly see through any lack of transparency - many of whom have waited years for diagnosis and likely to be already feeling vulnerable. However, these difficulties are not inevitable, and are compounded by the surrounding stigma. The diagnosis of FND can be delivered in a clear and straightforward way, just like any other medical condition, especially with demonstration of the presence of relevant clinical signs (Stone, 2015).

5.5. Racial differences in stigma surrounding FND

Disparities in healthcare access and treatment outcomes among different racial or ethnic groups is not well studied in FND, but has been studied in other neurological and neuropsychiatric conditions (Babulal, Zhu, & Trani, 2023; Rosendale, 2022; *The Lancet Neurology*, 2020). Disparities are likely driven by social determinants of health including education, socioeconomic status, access to healthy food, stable housing, access to healthcare and socioeconomic status (Rosendale, 2022; *The Lancet Neurology*, 2020). A large study showed that Hispanic and Black people in the USA are up to 40% less likely than white people to see a neurologist, even after adjusting for demographic, insurance and health status differences. Among those with known diagnosed neurologic conditions, Black people were more likely to be cared for in the Emergency Department and to have more hospital stays their white counterparts (Saadi, Himmelstein, Woolhandler, & Mejia, 2017). A recent review by Rosendale (2022) explores many social determinants of health in neurology, with a particular focus on issues of race and minority groups, outlining how many disparities results are “*inextricably linked to structural racism*” (Rosendale, 2022). Windon et al. (2024) describes the structural racism and discriminatory practices that underlie the underrepresentation of various groups in neurology research.

There was a less data in our review on stigma from low-income countries compared with higher income countries, which in itself indicates the under representation of FND in research in various regions (Naidoo & Bhigjee, 2021; Osman, Alsharief, & Siddig, 2020). Largescale international data show clear inequalities in terms of service availability in different regions (Hingray et al., 2017; Ladino et al., 2021). For example, patient care for functional seizures was provided on a “*self-pay basis*” in 50% of patients in low-income countries, compared with 5% in high-income countries (Hingray et al., 2017). Furthermore, individuals with FND were less likely to be followed up in middle or low-income countries, where there was also a marked disparity in access to psychological services (Hingray et al., 2017); or indeed any specialist services (Ladino et al., 2021). Several studies from Africa, Turkey, India and the USA show that a large proportion of people with FND come from lower socioeconomic backgrounds (Deka, Chaudhury, Bora, & Kalita, 2007; Folks, Ford, & Regan, 1984; Kuloglu, Atmaca, Tezcan, Gecici, & Bulut, 2003; Naidoo & Bhigjee, 2021; Osman et al., 2020).

There are findings in our review that may provide some insights into the intersectionality of stigma, race, gender and health disparities in FND. Intersectionality was coined by Kimberlé Crenshaw who described it as “*understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves*” (Crenshaw, 1989). Intersectionality has been described to likely play a role in many health-related issues – such as access to analgesia (Badreldin, Grobman, & Yee, 2019) and being involuntarily detained under mental health law (Barnett et al., 2019). A systematic review by Watson, Harrop, Walton, Young, and Soltani (2019) how culturally insensitive health services, stigma, and interactions with dismissive HCPs all impact on ethnic minority women’s ability to receive adequate mental health care. In general, it has been described how disparities in access to healthcare are associated with employment, education and economic status, where women are clearly disproportionately affected (Hosseinpour et al., 2012). Though reports of FND from low-middle income countries are

comparatively scarce, the majority of those diagnosed with FND are women, single and unemployed from lower socioeconomic backgrounds (Deka et al., 2007; Naidoo & Bhigjee, 2021; Osman et al., 2020). A recent South African study showed that FND was most common in women who were single, unemployed and of black African ethnicity (Naidoo & Bhigjee, 2021). These intersecting aspects of race, gender and economic disadvantage likely play a role in both increasing the risk of being diagnosed with FND and reduced access to specialist treatment, where women in particularly, are disproportionately impacted (McLoughlin et al., 2023).

5.6. Going forward

A key over-arching finding from our review was that interventions to tackle stigma in FND need to happen structurally. As outlined, the prejudice and discrimination that individuals with FND face is often ‘rooted’ in systemic or organisational deficits. This is in keeping with the literature on stigma reduction interventions in healthcare generally (Heijnders & Van Der Meij, 2006; Rao et al., 2019).

There is limited evidence on stigma reduction interventions in FND (MacDuffie et al., 2020). Heijnders and Van Der Meij (2006) outline the various stigma reduction interventions in HIV/AIDS, mental illness, leprosy, tuberculosis and epilepsy indicating the importance of these interventions being directed outside the individual or beyond ‘single-level’ interventions. They outline the importance of interventions that target institutional/structural aspects, among other areas, in order to effect sustained change. Similarly, Rao et al. (2019) outline how the current research for multi-level stigma reduction mainly lies in inter-personal or community interventions, and the lack of and need for interventions to be created on an organisational and structural level.

Keeping these principles in mind, going forward, there are several ways to remedy the outlined challenges.

One is to ensure FND is a core requirement in training curricula internationally from an early stage in training, for all specialties involved in the care of patients with FND. This has recently happened with the UK and European Union Neurology training curricula where it has justifiably moved from invisibility to a mainstream position (Ramsey et al., 2023). Communication protocols have been updated – for example revision of the framing of a “good news story”, and teaching ways to deliver the diagnosis in a clear and transparent way. As well as these aspects, it might be helpful to educate HCPs on stigma more formally in their training – it is probable that many are not aware of the influence of stigma on patient outcomes such treatment engagement, depression and quality of life. Ingrained stereotypes might hard to “unlearn” but professional and personal beliefs and values may over-ride these automatic thoughts and prevent harm. The importance of education and training is in keeping with recommendations and conclusions from existing literature on the topic of stigma in FND (Annandale et al., 2022; Foley et al., 2022).

Empathy has an inverse relationship with burnout in HCP (Wilkinson, Whittington, Perry, & Eames, 2017). It has been found that lack of empathy for patients can be driven by stress and overwork, and mocking attitudes may reflect HCP struggles (Tolchin, Baslet, & Dworetzky, 2016). Recruitment and retention of HCPs in healthcare systems is a global problem, but perhaps addressing underlying systematic issues such as burnout and bolstering support for HCPs could also be helpful in improving empathy and reducing stigma.

Many HCPs have outlined how they feel under-resourced and ill equipped to assess and treat patients with FND. Much of the time resource allocation is outside the diagnosing HCP’s authority and controlled by management or other departments. HCPs may struggle less if they felt they could be more effective in explaining the diagnosis, or have someone accessible to refer to (for example physiotherapy or psychotherapy). Clinical fallacy may exist – HCPs see only the patients who are most unwell – the “difficult” cases, and a balanced picture of recovery is not seen. One way to approach this is ensuring education

about positive cases, or better still positive case contact to counteract clinical bias.

It was clear from our study that services for patients with FND need to be prioritised – especially in deprived and rural areas. Better communication between disciplines and between agencies is also likely to improve satisfaction for the relevant care professionals, and help improve stigma and outcomes for patients. Moreover, research funding for effective and accessible FND treatments could be addressed - at the time of writing there were fewer than 15 trials actively recruiting for FND compared with hundreds or trials for MS, Parkinsons and epilepsy (clinicaltrials.gov).

On a positive note, there have been several advances – online resources, while not a replacement for treatment, have been found to be useful sources of information for patients with FND, their families and relevant professionals ([Gelauff et al., 2020](https://www.gelauff.com); neurosymptoms.org). FND society (fndsociety.org) is a scientific/professional organisation which are successfully disseminating and promoting educational content about FND. Patient led organisations such as FNDHope (fndhope.org) and FNDAction (fndaction.org.uk) have significantly helped both patients and the research community.

Patients with FND – both individuals and organisations, have been instrumental in drawing attention to FND through various channels. Some of these include holding awareness campaigns, hosting webinars with FND specialists and providing essential peer support. They have, and continue to disseminate accurate and helpful material online including patients sharing their journey (<https://fndhope.org/fndandus/>). In addition to generating energy and interest in FND on social media, patient organisations have played a pivotal role in research and played active roles in lobbying government for improved services for FND, the design of national care pathways (<https://www.nnag.org.uk/optimal-clinical-pathway-adults-fnd-functional-neurological-disorder>) and the update of educational websites (neurosymptoms.org) and apps (<https://myfnd.co.uk/>) for patients.

Furthermore, these individuals and groups have successfully navigated the complexities around the historical dualism that surrounds FND, acting as “translators” between HCPs and patients. Some have dedicated informative and inspirational sites that have significantly changed the landscape for both patients and professionals (<https://fndportal.org/>)(<https://fndrecovery.com/>). The continued involvement of such individuals and groups in awareness events, and their integration with HCPs, research and service design will be pivotal in transforming the negativity and misperceptions and that surround FND, and ultimately provide hope for people with this condition.

5.7. Gaps in stigma literature

Stigma is not something that can be easily measured quantitatively, but quantitative studies are helpful to highlight areas of need, and direct and measure targeted interventions.

The present review found that all studies were cross-sectional and there were no available longitudinal studies – these would be helpful in order to understand actual stigma outcomes, and also how stigma unfolds as a dynamic process. Only two studies used a control group, which comprised patients with epilepsy ([Karakis, Janocko, et al., 2020](https://doi.org/10.1016/j.jocp.2020.05.001); [Rawlings, Brown, & Reuber, 2017](https://doi.org/10.1016/j.jocp.2017.05.001)). The few quantitative measures that are available, only measure stigma in patients with functional seizures and not other functional neurological symptoms. Furthermore, the scales used are only validated in patients with epilepsy, and not in patients with functional neurological symptoms. At the time of writing there was no evidence of a validated scale to measure stigma in patients with FND. It would be helpful to formally explore stigma in patients with other FND symptoms outside functional seizures – given the existing reports from patients describing poor professional treatment and standards of care ([Nielsen et al., 2019](https://doi.org/10.1016/j.jocp.2019.05.001); [O’Keefe et al., 2021](https://doi.org/10.1016/j.jocp.2021.05.001)). Another area which appears to lack both data and awareness within the literature when it comes to FND, is the field of speech-language pathology. The consensus written

by [Baker, Barnett, Cavalli, et al. \(2021\)](https://doi.org/10.1016/j.jocp.2021.05.001), provides thorough and insightful recommendations, which are useful for professionals for both the assessment and treatment of such disorders. However, the consensus does not touch upon the topic of stigma related to such disorders. Additionally, studies that measure anticipated and internalised stigma would be important to undertake, given the evidence that these aspects of stigma drive lower levels of help-seeking and treatment engagement in other conditions ([Fox, Earnshaw, et al., 2018](https://doi.org/10.1016/j.jocp.2018.05.001); [Fox, Smith, & Vogt, 2018](https://doi.org/10.1016/j.jocp.2018.05.002)), and our review supported evidence of this.

We could not find quantitative stigma measures from the perspective of HCPs treating patients with FND, and a recent systematic review has demonstrated the need for an appropriate validated measure in this regard ([McGhie-Fraser et al., 2023](https://doi.org/10.1016/j.jocp.2023.05.001)). Largescale quantitative reports would be helpful to see the extent and focus of where stigma lies among HCPs and identify the key areas/specialties that would benefit from anti-stigma material. Acute care services (ambulance and emergency department staff) have been highlighted as being particularly worth of focus ([O’Connor & Reuber, 2021](https://doi.org/10.1016/j.jocp.2021.05.003); [Pretorius & Sparrow, 2015](https://doi.org/10.1016/j.jocp.2015.05.001); [Robson & Lian, 2017](https://doi.org/10.1016/j.jocp.2017.05.001); [Worsely et al., 2011](https://doi.org/10.1016/j.jocp.2011.05.001); [Yu et al., 2023](https://doi.org/10.1016/j.jocp.2023.05.002)), especially given they are often the first point of contact for patients.

Stigma affects caregivers of patients with FND and is related to caregiving burden, and patient QoL and anxiety ([Karakis, Janocko, et al., 2020](https://doi.org/10.1016/j.jocp.2020.05.001); [Karakis, Morton, et al., 2020](https://doi.org/10.1016/j.jocp.2020.05.002)). The positive impact of caregivers in providing a validating and supportive environment for patients with FND was evident in several studies ([Dickinson et al., 2011](https://doi.org/10.1016/j.jocp.2011.05.002); [Karterud et al., 2016](https://doi.org/10.1016/j.jocp.2016.05.001); [Pretorius, 2016](https://doi.org/10.1016/j.jocp.2016.05.002); [Rawlings et al., 2018](https://doi.org/10.1016/j.jocp.2018.05.001)). Future studies addressing caregiver’s needs, such as their level of burden and support, and the effects of their experiences of stigma are likely benefit both patients and caregivers. As highlighted previously by [Annandale et al. \(2022\)](https://doi.org/10.1016/j.jocp.2022.05.001), studies that explore stigma need to be sensitive to cultural components of the particular area – for example the idea that patients may be ashamed to tell others about treatments they had or beliefs they have about such that mental illness is something defective, or symptoms represent something “bad” such as witchcraft, or moral judgements around psychological therapies ([du Toit & Pretorius, 2017](https://doi.org/10.1016/j.jocp.2017.05.001); [Fouché et al., 2019](https://doi.org/10.1016/j.jocp.2019.05.001); [Moyon et al., 2021](https://doi.org/10.1016/j.jocp.2021.05.001); [Sarudiansky et al., 2017](https://doi.org/10.1016/j.jocp.2017.05.002)).

There were relatively few studies reporting on stigma experiences from the perspective of children and adolescents, however those that were available showed quite disturbing consequences – with young people missing school, losing friendships and carrying shame within the family. Given that adolescence is such a formative and developmentally important phase, the potential for both stigma and its consequences to damage emotional and social development is alarming. It is critical that further studies of the occurrence and impact of stigma in this group, and interventions to address these can be urgently prioritised. [Kozłowska et al. \(2021\)](https://doi.org/10.1016/j.jocp.2021.05.003) describe meaningful ways to change the culture of approaching and treating FND in children, reconceptualising FND in an effort to distance newer models from “outdated culture”.

Few studies report on perceptions of FND in the public domain. It is notable that the media portrayal of neurological disorders that are likely FND may often be inaccurate or negative, however there is evidence of increasingly positive news stories in recent years, with people with FND describing their condition and campaigning for services ([Porter, Alice news correspondent, 2023](https://doi.org/10.1016/j.jocp.2023.05.003)). The online domain has become increasingly popular for patients and their caregivers to obtain information and support, and interact about their illness with both HCPs and patient groups. Though there are likely beneficial aspects to the online space, representation of functional seizures in the online domain by self-declared professionals has also been found at times to be derogatory and offensive towards patients ([Myers et al., 2016](https://doi.org/10.1016/j.jocp.2016.05.001)). Focussed evaluation of stigmatizing and inaccurate perceptions of FND in the online domain, particularly among HCPs, is an understudied but valuable area to map out and direct interventions.

5.8. Strengths and limitations

This is an in-depth study including 127 studies from 148 countries, and all continents with 18,886 participants, 3751 of whom were patients with FND. To our knowledge at the time of writing, this is one of the first studies to systematically review the literature on stigma in FND, including and outside functional seizures. We acknowledge the broadness of our inclusion criteria, which we felt was necessary in order to capture the more covert, subtle facets of stigma, such as shame and prejudice, in addition to overt discrimination such as treatment disparities. Many of the included studies did not set out to explore stigma at the outset, however as the majority of our included studies demonstrate, stigma manifests in various ways that are not always directly obvious. We used known stigma frameworks to inform our method and analysis of stigma as an interactional and structural process. Our findings show there are significant gaps in the stigma literature and highlight areas for further study and intervention.

With regards to limitations, we were limited by the existing literature, as already discussed there are several gaps—such as the dearth of studies directly evaluating stigma from a quantitative or qualitative approach. While many qualitative studies showed themes relating to stigma, many did not set out to explore stigma specifically at the outset. The cross-sectional design of many of the studies does not allow the direction of causality between stigma and outcomes to be ascertained. In addition, many of the included studies were surveys and so may have selection bias.

With regards to the process of undertaking the systematic review, we only included studies in the English language and so may have missed several important studies where English is not the primary language. Furthermore, we did not include grey literature. Given the numerous patient-membership organisations and websites, this could be considered another potential limitation. Given that stigma is such a broad and complex there is the potential for selection bias for selected studies, however we tried to limit this as much as possible with disagreements resolved through consensus discussions between the authors.

6. Conclusion

Stigma is an intricate and complex process, occurring interpersonally and structurally. It ultimately affects provision of care for patients with FND. Future studies could be directed at examining the experience of stigma in different HCP groups, and different patient groups in addition to looking at the perceptions of caregivers, employers, the general public and the online community. Stigma-reduction interventions could then be created accordingly. While education and training curricula have improved in some locations, there is ongoing scope for progression in this domain. FND needs to be a higher priority for research funding so that safe effective treatments can be developed. Stigma is a systemic process and needs to be addressed at institutional levels so that appropriate and accessible care pathways can be created, giving patients with FND parity of esteem with other medical conditions.

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CRediT authorship contribution statement

Caoimhe McLoughlin: Conceptualization, Methodology, Formal Analysis, Writing-original draft, review and editing. **Laura McWhirter:** Writing, review and editing. **Katerina Pisezna:** Writing-review and editing. **Marina A.J. Tijssen:** Writing - review and editing. **Linke M.**

Tak: Writing - review and editing. **Alan Carson:** Supervision, Writing - review and editing. **Jon Stone:** Conceptualization, Supervision, Formal Analysis, writing - review and editing.

Declaration of competing interest

Jon Stone receives an NRS fellowship from the Chief Scientist Office, Scotland. He receives honoraria from UptoDate and personal fees from Expert Witness Work and runs a self-help website, www.neurosymptom.org, for patients with Functional Neurological Disorder. He is secretary of the FND society, and is on the medical advisory board of FND Hope UK and FND Action. Alan Carson reports being a paid editor of the Journal of Neurology, Neurosurgery and Psychiatry, and is the director of a research programme on functional neurological disorders, and he gives independent testimony in Court on a range of neuropsychiatric topics (50% pursuer, 50% defender). Marina A.J. Tijssen reports grants from the Netherlands Organisation for Health Research and Development ZonMW Topsubsidie (91218013) and ZonMW Program Translational Research(40–44,600–98-323). She also received a European Fund for Regional Development from the European Union (01492947) and a European Joint Programme on Rare Diseases (EJP RD) Networking Support Scheme. Furthermore, from the the province of Friesland, the Stichting Wetenschapsfonds Dystonie and unrestricted grants from Actelion, Ipsen and Merz. Laura McWhirter has received funding from Baillie Gifford and from the Scottish Government's Chief Scientist Office and is secretary (unpaid) of the British Neuropsychiatry Association, she also undertakes expert witness work in court cases pertaining to FND and other neuropsychiatric conditions. All other authors report no conflicts of interest.

Data availability

Data will be made available on request.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.cpr.2024.102460>.

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