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How stigma unfolds for patients with Functional Neurological Disorder

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ABSTRACT

Objective: The aim of this study was to explore experiences of stigma in Functional Neurological Disorder (FND) from the perspective of the patient as it manifests from the onset of symptoms, up to diagnosis and subsequently.
Background: The existing literature clearly shows that stigma exists for many patients with FND, and is associated with poorer quality of life. However, it is less clear how stigma unfolds, and how it can be alleviated.
Methods: We performed a qualitative interview study with patients who were diagnosed with FND, using data based on semi-structured interviews. Participants were recruited purposively via outpatient clinics. We analysed the data using a reflexive thematic analytic approach, through the lens of recognised stigma frameworks.
Results: 15 participants were included in the study, aged between 19 and 68 years, with varying presentations of FND. We identified six themes and 16 subthemes relevant to their stigma trajectory. We found that stigma unfolds through four main domains: 1) through their symptom experience; 2) through "othering" by the healthcare system; 3) through everyday interactions; and 4) from within the self. Across these four domains was a central theme of 5) stages of knowledge, which both fuelled and countered stigma. Lastly, 6) validation of the patient experience emerged as a theme that alleviated stigma.
Conclusions: Stigma did not unfold as a linear process, rather it came from multiple interacting sources. Interventions to target stigma could take the form of improved clinician training, communication, especially around point of diagnosis, and public interventions, co-produced with patients with FND.

1. Introduction

Functional Neurological Disorder (FND) is a common condition that can present in varying ways including, weakness, seizures, movement disorders and speech problems [1]. Though recognition of FND as a valid and treatable disorder is growing, it remains a neglected condition, influenced by outdated misperceptions and attitudes [2–4]. Training on the subject has been reported to be poor [5–7], and patients and clinicians report referrals to clinical services have been rejected based on the FND label [8–10].

A recent survey of 503 participants run by charity FNDHope, showed that **81.6% felt they had been treated poorly due to stigma** [11]. Stigma is a multi-factorial, social process and has been conceptualised in different ways [12–15]. Link and Phelan (2001) in their sociological model describe stigma as the co-occurrence of the following: labelling, stereotyping, separation, status loss, and discrimination, all occurring the context of power [12]. Stigma has been further considered as an interpersonal process involving *prejudice, stereotyping* and *discrimination* [13–15]. From the perspective of the person experiencing stigmatisation, stigma can be *experienced, anticipated* and/or *internalised* (self-stigma) [13,15]. It has been described how a collective social rejection of a group influences policy and healthcare planning, perpetuating a damaging cycle that has been described in other functional syndromes [16,17].

While there is a lack of longitudinal data on the outcomes of stigma in FND, stigma has been associated with depression and poor treatment engagement in other conditions [18 – 21]. Quantitative studies show stigmatisation is around 40% more likely for patients with FND than epilepsy – the latter also a highly stigmatised condition [22,23]. Stigma with functional seizures is associated with poorer quality of life and caregiver burden [22,24,25]. Reviews on this topic show there are several qualitative studies examining patient experiences of FND from

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Table 1
Clinical and demographic characteristics of participants (pseudonyms).

Pseudonym	Gender	Age	Clinical presentation	Symptom duration prior to diagnosis	Time from diagnosis to interview
Charles	M	46	Functional sensory symptoms	2.5 years	4 weeks
Una	F	68	Functional gait disorder Functional visual disturbance	3 years	2 years
Orla	F	51	Functional tremor Functional gait disturbance Functional cognitive symptoms Right upper limb functional numbness	11 months	2 months
Sam	Nonbinary	35	Dissociative seizures Functional cognitive symptoms	3 weeks	2 months
Grace	F	37	Bilateral functional leg weakness Functional achromatopsia Dissociative episodes Functional ankle dystonia	1 week	5 years
Ali	M	60	Functional left upper limb tremor	2 years	5 months
Brendan	M	48	Right sided functional weakness Functional speech disturbance	1 week	2 months
Rose	F	38	Functional tremor Functional left sided weakness Functional sensory disturbance Functional gait disorder	4 weeks	1 year
Poppy	F	34	Functional bilateral leg weakness 3 days post-partum	4 days	3 weeks
Hailey	F	19	Dissociative episodes Functional speech disturbance Functional weakness/paralysis	3 years	6 months
Maggie	F	29	Functional left sided lower limb weakness	2 years	5 weeks
Martha	F	53	Dissociative seizures	9 years	3 weeks
Laura	F	20	Dissociative episodes Functional sensory symptoms Functional tremor Functional speech problems	2 years	4 weeks
Norah	F	48	Functional left sided and generalised weakness Functional speech disturbance Dizziness	18 months	6 months
Bridget	F	39	Left sided functional weakness Left sided functional sensory disturbance Functional speech difficulties Functional cognitive difficulties	3 months	9 months

which stigma themes naturally emerged, but most studies did not aim to explore stigma specifically [2,3]. Furthermore, the majority of studies in this sphere relate to functional seizures – not covering the fuller spectrum of FND symptoms.

Therefore, while it is clear that stigma exists in FND, it is less clear where stigma originates from, how it unfolds, and how it can be alleviated. Increased knowledge about the development of stigma in FND could direct the formation of "anti-stigma" interventions, and potentially improve stigma-related outcomes for this group.

1.1. Aim

Therefore, the aim of this study is to explore experiences of stigma in FND from the perspective of the patient as it unfolds from symptom onset through diagnosis and thereafter.

2. Methods

2.1. Study design

We performed a qualitative interview study with patients diagnosed with FND using reflexive thematic analysis (RTA) [26,27]. We used the COREQ guideline for the reporting of this study [28].

2.2. Study approval

The study was approved by the University of Edinburgh and South-Central Hampshire A Research Ethics Committee (reference 21/SC/0418). 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 [29].

2.3. Participants

Participants were recruited consecutively via neurology/neuropsychiatry clinics. Inclusion criteria were as follows: 1) participant was willing and able to give informed consent; 2) of any sex/gender; 3) over 18 years; 4) their diagnosis of FND was given by a neurologist/neuropsychiatrist; 5) they were fluent in English (language of interviewer). We wanted to get a range of opinions and experiences related to stigma, and therefore employed purposive sampling to ensure diversity in age, gender, symptom presentation, and diagnosing clinician.

2.4. Recruitment

Prior to recruitment into the study, participants had to be diagnosed with FND by a neurologist/neuropsychiatrist. The clinician had copies of the participant information sheet and sought verbal consent from potential participants to be contacted by the lead researcher (CM), who waited at least 24 hours before contacting the potential participant to discuss the study and arrange a meeting time for consent and interview. Given that we were interested in stigma from symptom onset, we recruited patients as close to their formal diagnosis as possible (aiming for within four months) to reduce possible influence of a long recall gap on answers.

2.5. Interview structure and procedure

All interviews were recorded using a secure encrypted Dictaphone

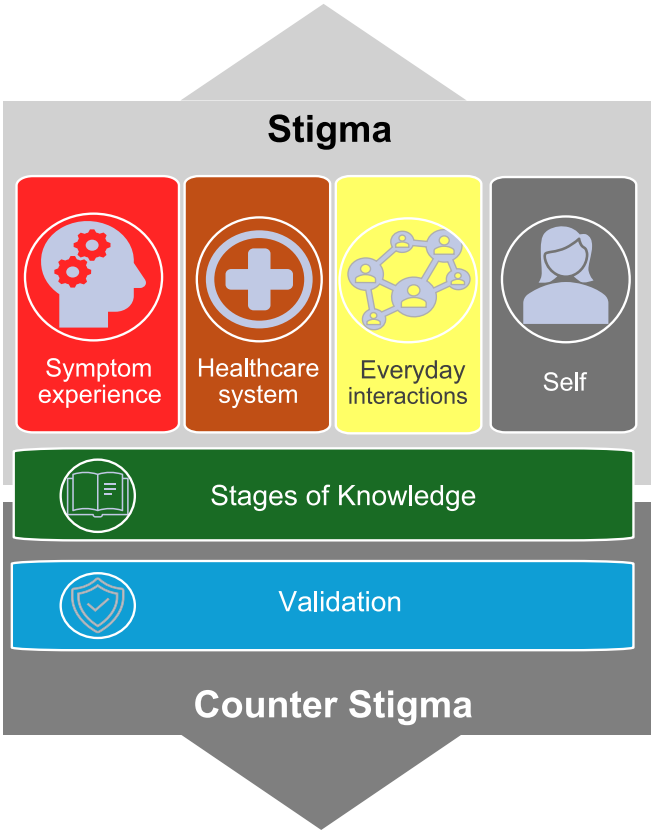

Fig. 1. Core themes depicting how stigma unfolds for patients with FND. Stigma unfolds through four main domains, impacted by stages of knowledge. Stigma was alleviated by increasing knowledge and validation of the patient experience.

following informed written consent. Each interview lasted 45 to 90 minutes. Questions were informed by the various components of stigma as it has been described in the literature [12–15). We chose open questions about patient experience as not to be leading, deliberately not mentioning stigma, giving space for both positive and negative experiences. See Supplementary Material Appendix 1 for discussion guide. We checked the patient's medical record to verify the diagnosis and history (including time from symptom onset and diagnosis to interview).

2.6. Analysis

We analysed the data using a reflexive thematic analysis approach [26, 27, 30). To reduce the risk of bias, we strived to ensure the analysis remained grounded in the data, remaining cognisant and reflective about existing assumptions from our clinical and research experience. CM (liaison psychiatrist), JS (neurologist), AC (neuropsychiatrist) and TOH (general practitioner) are involved in the clinical care of patients with FND, and BMF (sociologist) has extensive experience in qualitative research. All researchers are involved in researching stigma as part of the ETUDE program [29].

The audio-recorded interviews were transcribed verbatim and analysed independently by two researchers (CM and BMF), using MaxQDA 2022 software. We followed six iterative steps, namely; familiarisation, coding, generating initial themes, reviewing and developing themes, refining, defining and naming themes, and writing up [27,30]. We regularly compared our analysis, clarifying differences and refining our codes, themes and subthemes. We wrote memos throughout to capture our ideas and reflections on codes and themes as they emerged. We further discussed our analysis with experts in the field (TOH, AC, JS). We discussed differences in coding until consensus was reached.

3. Results

Nine interviews were conducted face to face and six interviews via secure video platform. After 15 interviews, using the latest coding framework, no new categories were found, and we considered saturation was reached. We selected quotes which we considered depicted a theme/subtheme well.

3.1. Participant characteristics

There were 15 participants in total, 11 identified as women, one as non-binary and three as men. Participants were aged between 19 and 68 years. All diagnoses were confirmed by a consultant neurologist (five consultants in total), often after it had been raised as a possibility in the emergency/primary care setting. See Table 1 for clinical and demographic characteristics of participants. Twelve patients were recruited within six months of diagnosis. In order to maximise sample variation, the remaining three were recruited nine months to five years post-diagnosis.

3.2. Main themes and subthemes

We found the patient experience of stigma did not unfold as a linear trajectory. Rather, six key themes dynamically interacted with each other. Stigma unfolded through four main domains: 1) their *symptom experience*, 2) *"othering" by the healthcare system*, 3) *everyday interactions* with friends, family, colleagues and online, and 4) from *within the self*. Across these four domains was a central theme of: 5) *stages of knowledge*; and lastly, 6) *validation of patient experience* emerged as a theme that countered or opposed stigma (see Fig. 1). Furthermore, we found 16 subthemes within these themes, see Table 2. **Case Boxes 1–3** are examples of stigma narratives depicting the trajectory of stigma themes. Note, these are not true cases, but adapted from individual cases to protect anonymity.

3.3. Main themes and subthemes

3.3.1. Theme 1. FND symptom experience

The experience of having FND symptoms gave rise to stigma – due to their conspicuous nature, variability which was not easy to explain, or conversely because they appeared "normal", with no disability. Comments from others led patients to become self-conscious or "noticed": *"for me it is just the normal … until somebody points out that it's weird*" (Maggie). Several patients expressed concern about how their symptoms might be perceived; *"I suddenly started taking tremors… …it was like does she think I've got the DTs [delirium tremens] or something"* (Orla). The variability inherent in FND led to patients feeling doubted around the legitimacy of their experience; *"he asked me to walk…it's really hard for someone to diagnose something when you look normal and walk normal"* (Una).

Many symptoms felt vague and were hard to articulate. Being unable to satisfactorily communicate the symptom challenged the credibility of experience, which led to patients feeling they needed "proof". *"…at times I have thought if I had some sort of proof that my condition is like disabling I would feel more comfortable sitting on disabled chairs"* (Laura). Many patients had the impression that others thought they could control their symptoms. For some it was felt implicitly; *"they do make you feel like it's all in your head, you're dreaming this, you're making this happen*" (Norah). For some the loss of control during episodes hampered social participation, forming a cycle of decreased confidence and exclusion: *"I may have had a few episodes of not being able to talk … having to kind of withdraw from the classroom….it does feel embarrassing that I don't have control over it"* (Hailey).

3.3.2. Theme 2. Self

Self-stigma emerged as a significant theme, where patients

Table 2
Main themes and subthemes with illustrative quotes.

Theme	Subtheme with illustrative quote
1. **FND symptom experience**	a) ***Visibility of symptoms*** *"when you can hear other people talking over you and about you yeah … they couldn't believe they had seen something like this before…I'm literally kicking everything out; my arms, my legs, …I just feel really hurt"* - Martha
	b) ***Invisible*** *"I was out in the garden and there was a guy that I've no seen for absolutely years and he walked by and he made some sort of comment about there's nothing wrong with your legs you can walk fine there… I think people just find it difficult because like one day I can be in a wheelchair the next day my walking can be pretty decent"* - Grace
	c) ***Voluntary control*** "*There is a little bit of shame in losing control … you can't help but feel embarrassed because you have lost control…that is something that I spent days in the hospital trying to come to terms with…"*- Sam
2. **"Othered" by health system**	a) ***Healthcare professional attitudes*** *"the experience with the GPs about it hasn't been very…ehm and it just, it actually upset me quite a fair bit… he did say … could you not walk in and I'm like I cannae. made me feel like he was saying it was all in my head and I was making it up and stuff and I was just sort of like why would anybody make this up…."* - Grace
	b) ***Point of diagnosis*** *"it was like a kick in the back because it wasn't even really a consultation, it was a case of … suddenly oh you've got FND, it's almost like just putting me in a bracket, you've got FND here's the website, go away"* -Charles
	c) ***Functional is left out and "lesser"*** *"I kinda got the general feeling that the way to treat FND is to ignore it and so do ignore it means to not talk about it so … what professional do I get to say this is happening, this is hurting"* -Bridget
3. **Everyday interactions**	a) ***Friends and family*** *"I feel like my mum is the sort of person that always belittled my health…um she… she would say… 'I don't know if I should believe you anymore because what if you're making it up'"* -Laura
	b) ***Work*** *"I haven't told um the people I work for and I don't know if they would let me continue to work there if they knew…part of me thinks that I would be written off … like they won't trust me to do things…because…its difficult though because there are times when it would be useful for them to know"* - Hailey
	c) ***Online*** *"I never heard of it and it wasn't until I started reading [online] oh my god, oh my god that's when I just lost all respect, all my self-respect…just reading things like you're nuts basically*" – Norah
4. **Self**	a) ***Devaluation*** *"I feel like a useless piece of … flesh that doesn't work properly*" - Una
	b) ***Shame*** *"it had a huge impact on my self-esteem because it made me feel my on my god you are a complete fruit loop, I mean you made this happen…you are making this happen to yourself and it made me, it was actually yeah, I ashamed of myself"* -Norah
	c) ***Strength*** "*I've learnt a lot through the process, I think probably ehm value myself more"* -Orla
5. **Stages of knowledge**	***a) Misperceptions/public awareness*** *"I've been going back and forward to the doctor with but nobody knew what was wrong because I think there is not enough knowledge about it, it's a really like underrated…. because you say it to folk, I've got an FND, and they look at you like you have got three heads like what's that"* - Rose ***b) Importance of explanations*** *"and then leaving from there I felt a little bit more satisfied that somebody took it more seriously…and understands that there is a problem there, but we don't know what…I think the way to explain things saying it could be this, it could be that… he says right what will we do with you, we take a step at a time"* – Ali
6. **Validation of patient experience**	a) ***Within professional context*** *"She … kind of propped it up, you know…and didn't make me feel ashamed…I think because she was the first doctor that actually made me feel like that, I then felt a bit better about having it, does that make sense"* - Norah
	b) ***Within wider context*** *"I was really lucky I got quite a positive from my friendship group and from my family…other people have said your just lazy it's just a title, you….you've looked for this…a few like my closest friends have downloaded the app and they're like that how you are feeling today… is there anything we can do, can we make it better like"* - Rose

internalised negative beliefs and attitudes about FND. It is possible that this self-stigma reflected perceived stigma from professionals and others. In some cases, self-stigmaled to disturbed self-identity and devaluation; "*it's kind of that weird imposter syndrome….am I trying to make things more wrong with me… other people have it worse"* (Hailey). This self-judgement often abated when given the official diagnosis: *"it was a relief when I found out what it was because I thought ehm, I thought I was causing it""* (Orla). Many described themselves in derogatory terms – as if their FND represented something intrinsically deficient; "*I am wrong*" (Una). Several patients internalised negative stereotypes such that people with FND were malingering or crazy. Some described feeling undeserving of care or healthy relationships, or judged themselves for perceived inabilities. *"I think it's stolen my life…who would want this because realistically nobody, nobody wants to have to deal with somebody that's like this"* (Bridget).

This feeling of shame affected how patients would choose to interact with others. Some patients became afraid to socialise, losing confidence and amplifying self-stigma; *"I've lost friends…because of it, so it's kinda … she's not got a lot to say"* (Bridget). One patient didn't want to go out in case anyone could *"identify a weakness""* (Orla). Shame led to many not disclosing their diagnosis, linking to anticipated stigma around misperceptions of FND; *"I'm not ashamed to tell people that I have ME uhm but if it ever gets to that stage with FND I don't know… there is so many people out there insisting that it's Freud's conversion disorder"* (Norah).

Case boxes 1–3
Describing typical stigma trajectories (fictional), adapted from individual cases.

Case 1. Leo developed weakness in his leg and face and thought he was having stroke. He felt worried and self-conscious.	**Symptom experience**
After a few days in hospital, he was suddenly diagnosed with FND and promptly discharged. He did not understand what the diagnosis meant, as it all felt really rushed. He went to his GP after discharge to get more information, who told him he must accept the diagnosis or he would not get better.	**Othering through healthcare system**
Leo was confused by this so so looked FND up online. He found the online information scary and demoralising – where experts in the area were discredited and people saying FND was a pseudonym for faking.	**Stages of knowledge**
He was referred for regular physiotherapy where the therapist worked closely with him for over a year, educating him about his condition and helping him with exercises to get his power back.	**Validation**
He is able now to do the activities that are important for him, and feels the diagnosis of FND has made him stronger.	**Self**

Case 1 (fictional)

Case 2. Mary dreaded the loss of control that happened whenever she had a functional seizure. She felt scared and also feared she appeared strange to others.	**Symptom experience**
Her friends called her weird, and she internalised this negative attribute.	**Everyday interactions**
The emergency staff discharged her whenever she came to the Emergency Department with no diagnosis, leaving Mary with no words to explain her condition to others.	**Othering through healthcare system**
By the time she got to see neurologist several months later, she had withdrawn a lot socially partly due to shame around losing control.	**Self**
Her neurologist was able to spend time giving her a clear explanation and diagnosis, with a care plan tailored to her individual needs. She stopped reattending ED, and having a clear words for her diagnosis with analagies, empowered her to explain what was happening when the symptoms occurred.	**Stages of knowledge**

Case 2 (fictional)

Case 3. Farah worked in healthcare and started to experience dissociative events where she felt strange and unreal. Over the next few weeks, she noticed she was unable to remember things, felt dazed, and got lost on the way home.	**Symptom experience**
She was afraid to tell her healthcare colleagues as she suspected they held negative preconceptions of functional disorders.	**Everyday interactions**
She went to her GP where she felt dismissed, as they did not give the perception there was any urgency to her presentation, despite her being too afraid to work and drive.	**Othering through healthcare system**
She started to believe she was imagining her symptoms and blamed herself for being stressed.	**Self**
She had a helpful interaction with her neuropsychologist who acknowledged the seriousness of her condition and	**Validation**
explained it in terms that made sense to her, integrating the connection of mind and body.	**Stages of knowledge**

Case 3 (fictional)

Though many experienced self-devaluation, several patients also adapted in positive ways to stigma-related difficulties, becoming more assertive and assured of their worth. Many harnessed inner resilience, choosing to ignore negativity and focus on recovery. It was often through the process of accepting the diagnosis, allowing it to be integrated as a valid part of themselves that allowed strength and confidence to blossom; "*I think generally it's actually made me a stronger person…ehm and like I say I've, I'm a completely different person for what I was before FND…ehm and I know it's rough at times but it's my life has changed for the better*" (Grace).

3.3.3. Theme 3: "Othered" by the healthcare system

Through interactions with the healthcare system, many patients experienced a feeling of being different or less legitimate than patients with other medical conditions. This "othering" happened in both subtle and more explicit ways, and led patients to feel set apart and separated on the basis of having FND. This process of othering mainly occurred through negative professional interactions, though it was not the only route. For several patients, the route to diagnosis was protracted and difficult – for example they saw multiple specialists, had to seek care privately or attend the emergency department repeatedly for years before a diagnosis. Many perceived a sense of confusion about FND from professionals, in contrast to other conditions they sought help for.

While not arising for every patient, negative professional attitudes were quite formative. A common scenario involved an invalidating consultation where there was a discordance between patient experience and what professionals saw as "normal"; *"I feel like I was gaslit a lot by medical professionals…was essentially making things up… because everything came back as normal"* (Laura). This was more strongly described in primary care or emergency department (ED) settings. There was a general sense that patients were bothersome and unwanted, leading to feelings of rejection; "*you can almost feel them sighing"* (Norah). Some interactions represented more serious derision and ridicule: "[its]*as if you didn't exist, you're down …they're mocking around you… they said she is just an attention seeker"* (Martha).

FND was further set apart throughout the process of diagnosis. While some found it a positive moment, many felt confused and isolated: *"professionals can be…um put you in the deep end and see if you start swimming …. I think it's better to say that sounds like something is wrong… you're not completely crazy"* (Hailey). The diagnosis was often delivered in unusual ways – not mentioned in the work-up, rushed or sprung as a surprise. In some cases, a website appeared to entirely replace a satisfactory consultation. One patient was told that diagnosis was her choice; "*it was quite strange the whole process you don't have to be diagnosed with this…it's your choice"* (Hailey). Another had an opposing experience where diagnosis felt forced; *"…got to the point where I ended up crying like…I don't understand, she was demanding me just to confirm I believe that I had FND*" (Bridget).

FND was almost never mentioned in differential diagnosis. When it was, it felt vague and mysterious; *"Nobody mentioned FND… it's so…I don't want to say niche but …different, you know"* (Una). There was an implication that despite frightening symptoms, FND wasn't serious; *"I didn't feel as though there was any urgency… and to me … I felt like my memory was leaving me"* (Sam). While many were open to psychological components in their formulation, simply attributing FND to mental illness felt invalidating, and an excuse for professional inaction; *"ehm it just felt like a dismissive kind of you've got FND eh…saying without saying it's all in your head …it's all because you were abused…it's very easy for people to kind of block you"* (Bridget). Once the diagnosis of FND was given, several were discharged with no perceived plan, a contrast to other conditions.

3.3.4. Theme 4. Everyday interactions

While family and friends were often supportive, several patients experienced stereotyping and dismissal, threatening the veracity of their condition; "*As much as my family have grown and become supportive there were moments when they said 'get up just get up, go to school you're just being dramatic', so I guess that did change when we talked to the psychologist"* (Hailey). Several patients anticipated stigma from colleagues, which led to patients not disclosing their diagnosis, especially those who worked in health and social care settings; *"I was worried that they would be judgemental…I somehow believed and still do believe, that they will take the seizure bit seriously but not the functional bit"* (Sam). One patient described feeling stereotyped by colleagues, which they linked to them not believing the functional impairment with FND; "*they were like nah you just want time off …you just want extra benefits…I've never had a benefit in my life"* (Rose). Some gave up work altogether impacting sense of identity which again, triggered a cycle of reduced self-esteem and social exclusion.

Several patients used the online space to interact about FND, and for several their stigma experience really ignited in this domain. Reading inaccurate posts drove self-doubt, which was exacerbated when professionals were discredited; "*do you know what was very unhelpful recently… …from a COVID group…eh and basically it was to do with FND research being led by [name removed] basically he is a fraud, they are all frauds uhm… that just set me back just all the way* (Norah). It also arose when they encountered individuals whose experience did not fit at all with their own, leading to confusion and fear; *"I was like …wait a minute here …but I'm nothing like these guys on this website so what are they talking about*" (Charles).

3.3.5. Theme 5. Stages of knowledge

A consistent issue in all interviews was the lack of awareness of FND; *"if you had something that people have heard of they would be more sympathetic perhaps? But I think when you have something that people haven't heard of, that brings its own challenges"* (Una). It was demoralising and "othering" for patients to try and explain FND difficulties that were already hard to verbalise, to people who had never heard of it. The knowledge that did exist often reflected inaccurate, outdated models. Several patients educated others about misperceptions, adding additional burden; *"when I first told my best mate it was like, 'this is fake'…but in the end he went away and read it and he was like ken this actually does make sense"* (Brendan). (Please note "ken" is a common word used in Scotland which means "know"/"you know").

The importance of having an explanation that fit their experience was outlined in all interviews, helping them feel less "othered" and more confident in narrating their difficulties to others; *"but just seeing the professional for maybe forty minutes like changes everything, I was like oh wow ok, that was easy once I actually was given the proper care*" (Laura). It also helped them with any self-doubt/blame that FND was their fault. All patients were realistic about how a clinician might not have all the answers, expressing a desire for open communication. Several commented on the lack of knowledge in the medical profession*; "I think they could maybe do with like more training in GP surgeries…but that just I think the general medical world could do with more education"* (Rose). Online information had the potential to be overwhelming and stigmatising, though it was often useful. However, FND remained elusive and hard to grasp for many; "*I don't find it hard to explain to them, I find it hard that they don't understand what I'm telling them"* (Ali).

3.3.6. Theme 6. Validation of patient experience

The majority of patients commented they felt understood and supported by professionals at some point in their trajectory. These professionals comprised several disciplines, and usually had existing knowledge of FND. When this happened, they felt that they and their FND experience were seen as valid and worthy of attention, in contrast to what they had heard before, read online, or internalised. *"I think it was a relief…that I was taken seriously if I'm honest and it wasn't just all in my head again*" (Orla). Specifically, taking time, being appreciated as an individual and demonstrating visibility of clinical signs were helpful. Having a follow-up appointment and a clear treatment plan were important*: "it just meant that…something significant was happening despite*

the vagueness of the diagnosis…there was a clear way of way of getting help" (Sam).

Despite some stigmatising experiences, family and friends they were also frequently sources of recognition and understanding. Families particularly were key in supporting patients; "*when I am at home I have people around me that understand and recognise when I could be having a day when I am more likely to have one of these episodes"* (Hailey). Given the difficulties grasping FND, it was often a journey for family/friends to get to the stage where they could be understanding and supportive, usually influenced by desire to learn more about FND; "*my partner … he has got the app on his phone and he's…he's like I don't understand it…I but I will learn, if there is anything I can do to help…he's been absolutely…it's been positive*" (Rose).

4. Discussion

4.1. Main findings

Our findings show that stigmatisation experienced by patients with FND unfolds and interacts though four main domains – the symptom experience, self, healthcare system and everyday interactions. FND was often perceived as something different, "niche", and mysterious. Patients were often not given the diagnosis in a typical way, and had to educate others about their condition, leading to distress, "othering" and feelings of separation. A negative cycle often ensued, where patients internalised their difficulties, feeling unable to share with people who could potentially support them, leading to avoidance and exclusion. Knowledge was a key factor throughout the process – a lack of knowledge propelled stigma, but was also an effective tool in countering stigma. Validation – recognising and affirming the patient and their experience was helpful towards alleviating stigma. While clinicians were not the sole origin of stigmatising experiences; nonetheless in all these cases, they played a powerful role in helping allay them.

4.2. Comparison with previous literature

Our findings reflect the literature on stigma in FND [2,3,31,32], and provide some further insights. We found that patients with a range of FND symptoms, including speech disturbance, visual and cognitive symptoms experience stigma, phenotypes which have not been explored much in this realm previously. We found that negative mental health connotations associated with FND, while present, did not emerge as prominently as represented in the existing literature [2,3,31,32] and patients in this study were open to psychological components to their formulation and treatment. Furthermore, while concepts related to the self and identity have been explored previously in relation to FND [3] the weight of self-stigma and its impact on patients with FND were pertinent findings in this study.

The finding that stigma arises from everyday interactions is elsewhere in the literature in relation to functional seizures [2], with patients describing experiences of being misunderstood and stereotyped, similar to this study. However, these findings are usually overshadowed by explicit negative healthcare interactions which are far more pervasive in the literature [2,3,32]. While negative healthcare interactions were significant in our study, they presented as one of several manifestations of the broader culture of the "othering" of functional within the healthcare system. Furthermore, while there is some evidence that representation of FND online is derogatory and offensive towards patients [33], the burden of online stigma experienced by patients is an unexplored area in the literature, and a further important finding in our study.

4.3. Strengths and limitations

Our findings are limited to a small sample, however, despite this, this sample was diverse in terms of gender, age and clinical presentation. There may be differences between those who decided to participate and those who didn't. Though we wanted to recruit patients as close to possible as diagnosis to minimise potential recall bias, a minority (three) were recruited nine months to five years post-diagnosis. We felt this was acceptable – the criterion of duration between diagnosis and interview was not in our formal inclusion criteria, as we felt it was more important to maximise sample variation, and include rarer presentations such as functional visual symptoms. Nonetheless, this could be regarded as a potential limitation. Our findings were obtained from a predominantly white UK sample, meaning we did not obtain experiences from other patient subgroups. We used open-ended questions which were not leading, allowing for a range of stigma-related experiences to emerge. Our sample was limited to a small region, where some clinicians have a particular interest in researching and treating FND, though we did recruit from a range of clinicians, whose expertise lay outside FND. However, because of this, it is possible that other sources of stigmatisation were able to emerge as well as healthcare professional interactions.

4.4. Implications of results

Our findings suggest there are numerous ways that stigma could potentially be reduced. Given how stigma occurs as a cyclical process, it is likely that addressing one key area might impact another. The crucial role of the clinician has been described, linking in with the aspect of power that is inherent in the stigma process [12]. In addition to the frontline patient interaction, clinicians are in a position to tackle stigma on a structural level, such as advocating for research/service funding and designing training programs and health policy.

The findings of this study suggest that training for clinicians could be improved, so FND is not perceived as "lesser" or "other". FND should be placed within formal core curricula, at an early stage in training, for all relevant specialties involved in the care of FND, (for example nursing, paramedical training, physiotherapy, speech and language therapy, occupational therapy and medical social work). In addition, the "hidden curriculum" [34] is also worth serious consideration by educators. This more subtle method of learning, which includes processes such as role modelling and informal conversations, is an influential vehicle for perpetuating stereotypes, but can serve to impart helpful attitudes.

Regarding the area of clinical communication, patients would benefit if clinicians imparted the diagnosis in a compassionate and confident way. There have been some studies focussing specifically on this area with positive results [35–37]. Mentioning FND as a potential in the differential in the same way as any other condition would be useful during work-up. It could be possible that clinicians are aware of the stigma and misperceptions surrounding FND, and are therefore reluctant to mention FND as they are worried about alienating the patient or engendering mistrust. It is possible too, that clinicians may fear missing a diagnosis such as multiple sclerosis or epilepsy, which may be perceived as a larger clinical error than missing FND. That said, in a systematic review of 1466 patients with FND, the proportion of misdiagnosis was less than 4% after an average of 5 years of follow-up [38]. Even after lengthy follow-up, the diagnosis remains stable—a recent 14-year follow-up study described a diagnostic revision rate of 1% [39]. Indeed, misdiagnosis occurring in the opposite direction (diagnosing FND as epilepsy for example) has the potential to be harmful [40]. Regarding other areas of communication, it is important to validate the patient experience and where possible, allow time for a follow up appointment. Regarding the use of unguided internet self-education, directing patients to a single website is an approach that needs to be used thoughtfully, as an adjunct to appropriate care. While patients find this type of self-education valuable, it is not a replacement for treatment [41].

Regarding the symptom experience and self-stigma, it is worth remembering that patients are unlikely to bring forward these concerns. Self-stigma has been discussed often as occurring in tandem with

perceived stigma – an individual's recognition that the healthcare system and public hold prejudice and will discriminate against them because of their presentation and diagnostic label [42]. Therefore, clinicians may have a role in propagating self-stigma for patients, further highlighting the pressing need to address negative professional attitudes and public misperceptions. Furthermore, it would be helpful to be cognisant of other potential origins of self-stigma and explore further if necessary, or explain more specific aspects of FND that might bring this about. For example, the variability and distractibility inherent in FND could be explained so people understand why the symptoms are not constant or always visible. It is important to balance a sensitive approach while also not "othering" the patient further.

Regarding stigma from other sources, maintaining an open dialogue where possible with work, family and school/university could be helpful. Family and friends could be included more actively in the process of diagnosis and treatment, educating them alongside the patient. Maintaining communication with work, schools or universities such as written advice on what do to during seizures, or outlining a patients' abilities or restrictions could be helpful, to increase inclusion and reduce the potential of feeling "othered" in these domains. Regarding online stigma, advising patients and their caregivers about the fallacies/outdated models in the public domain and emphasising the selective trustworthiness of sources could also be useful.

Improving public knowledge around FND is paramount, and much work led by patients and professionals has already been done in this regard [43,44]. The online domain will continue to be used by patients to interact about their illness and though it can be harmful, there are beneficial aspects to the online space. This is an emerging area of importance in functional disorders [45,46]. Future studies could assess the accuracy of online information and perceptions of FND in the public domain, and direct interventions accordingly.

Going forward, all the above interventions should be co-developed/delivered by patients with FND. In the last few years, individuals and groups have successfully navigated the complexities around the historical dualism that surrounds FND, acting as "translators" between clinicians and patients [11,44]. Their continued involvement will be critical in transforming the misperceptions throughout the FND landscape.

5. Conclusion

Stigma unfolds as a layered process, influenced by surrounding structures, relationships, what is held internally and what has gone on before. It is alleviated by increasing knowledge and validating the patient experience. Interventions to target stigma could take the form of improved clinician training, communication, especially around point of diagnosis, and public interventions, co-produced with patients with FND.

Data sharing statement

Source data will not be shared, given potential for patients to be identified on transcriptions. A copy of the process of analytical codes and themes can be shared upon reasonable request.

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CRediT authorship contribution statement

Caoimhe McLoughlin: Conceptualization, Methodology, Formal analysis, Writing – original draft. **Brodie McGhie-Fraser:** Methodology, Formal analysis. **Alan Carson:** Conceptualization, Supervision. **Tim Olde Hartman:** Formal analysis, Supervision. **Jon Stone:** Conceptualization, Formal analysis, Funding acquisition, Supervision.

Declaration of competing interest

CM and BMF receive funding from the EU Horizon 2020 Marie Curie Sklodowska program grant number 956673. AC is an associate editor of Journal of Neurology, Neurosurgery and Psychiatry (paid) President of FND society (unpaid) and gives expert testimony in Court on a range of neuropsychiatric topics. JS reports honoraria from UptoDate, personal fees from expert witness work, grants from National Research Scotland and Wellcome and runs a free self- help website, www.neurosymptoms.org, for patients with FND. ToH has no declarations of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jpsychores.2024.111667.

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