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Functional neurological disorder: A qualitative study exploring individuals' experiences of psychological services

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Abstract

Objectives: Individuals with a diagnosis of FND report experiencing stigma in medical settings, however, there is a paucity of research exploring their experiences in psychological services. The aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with FND.

Methods: This study utilised a qualitative approach with data collected from semi-structured interviews ($n = 15$) and analysed using reflexive thematic analysis.

Results: One superordinate theme, 'the stigmatised self within the therapeutic relationship', and five interrelated subthemes were identified: 'internalised stigma and self-doubt', 'selective disclosure to professionals', 'perceptions of psychological explanations', 'having to educate the professionals' and 'attunement and trust within the therapeutic relationship'. Positive therapeutic relationships were perceived to mitigate the impact of these perceived barriers. The conceptualisation of FND and the perception of how this was responded to by services and professionals was a central tenet throughout the related themes.

Conclusions: Intra-personal, interpersonal and organisational stigma impact access and engagement to psychological treatment. The findings of this study highlight the need for increased training provision for practitioners with a focus on actively challenging FND stigma within services at both an individual and systemic level.

KEYWORDS

functional neurological disorder, psychological services, stigma

Practitioner Points

- Internalised stigma and perceptions of stigma within the therapeutic encounter are barriers to accessing and engaging with psychological services.
- Some individuals with FND experience psychological explanations of their symptoms as blaming. Psychological formulations that bridge the gap between mind–body dualism may be helpful in reducing perceptions of blame.
- Positive therapeutic relationships in services may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention.

INTRODUCTION

Functional neurological disorder (FND) is classified as an 'acute presentation of neurological dysfunction involving the motor and sensory nervous system' (Hudson, 2020, p. 1). Despite these symptoms, medical investigations (e.g., MRI and EEGs) do not show any structural abnormalities, indicating that symptoms may instead be the result of an issue with the functioning of the nervous system (Bennett et al., 2021). Individuals with FND-type symptoms usually present to Neurology services in the first instance, with FND representing one of the most common reasons for new patient referrals in these settings (Stone et al., 2010). Although true prevalence is unknown, estimations of annual incidence are approximately 4–12 out of 100,000 (Carson et al., 2012; Stone & Carson, 2015). Although gender ratios vary dependent on age of onset (Lidstone, Costa-Parke, Robinson, Ercoli, & Stone, 2022; Lidstone, Costa-Parke, Robinson, Ercoli, Stone, Ahmad, et al., 2022), women are two to three times more likely to receive a diagnosis of FND (Matin et al., 2017), the reasons of which are currently poorly understood (Baizabal-Carvallo et al., 2019). There is some evidence to suggest FND is more prevalent in lower socioeconomic groups (Ali et al., 2015; Owens & Dein, 2006), although other demographic variables such as ethnicity are not considered to be a contributing factor (Ali et al., 2015). Chronic stress and psychological trauma have been consistently linked to an increased risk of developing the condition with a recent meta-analysis concluding that adverse life events were eight times more common in those with FND compared with non-clinical controls (Ludwig et al., 2018). However, it should be noted that epidemiological studies related to FND are in their infancy and thus must be considered in the context of their methodological limitations (e.g., small sample sizes and retrospective data that increases the risk of selection bias). Furthermore, not all individuals with a diagnosis of FND report experiences of adversity or trauma (Ludwig et al., 2018).

The variance in diagnostic labels (e.g., FND, conversion disorder, psychogenic seizures, functional/dissociative seizures, non-epileptic seizures, functional movement disorder) highlight the etiologic uncertainty of this presentation (Garrett et al., 2020). FND was previously referenced under the umbrella term 'medically unexplained' and more recently 'persistent physical symptoms'. Causal mechanisms for these types of presentations are complex and widely debated, although they are often considered through the lens of the biopsychosocial framework; the interaction of biological and psychosocial etiological factors (Brown, 2007) and the stress-diathesis model (Keynejad et al., 2019). Thus, gold standard multi-disciplinary intervention involves both psychological treatment and physical rehabilitation (LaFaver et al., 2021). However, there is currently no UK National Institute of Health and Care Excellence (NICE) guideline for the treatment of FND, although reference is made in the quality standards

that there should be 'the offer of psychological support where appropriate' (NICE, 2021). Despite this recommendation, there is a lack of consensus on the most appropriate evidence-based psychological treatments for FND. Systematic reviews of several treatment modalities have found promising emerging evidence for the effectiveness of, cognitive behavioural therapy (Gutkin et al., 2021; Kleinstäuber et al., 2011), psychodynamic therapy (Gutkin et al., 2021), acceptance and commitment therapy (Hughes et al., 2017) and EMDR (Staton et al., 2022), although firm conclusions on treatment efficacy cannot be drawn due to methodological limitations of the current research. As a result of this, psychological treatment provision in UK services can vary greatly. Whilst there are some specialist FND services within the National Health Service (NHS), a large portion of those with a diagnosis of FND will be referred to general psychological services due to limited specialist service provision and increased waiting times (Walker, 2019).

When considering the experiences of those accessing healthcare services for FND, current research has focused solely on medical settings. Individuals with FND report feeling dismissed and disbelieved in these settings (Burke, 2019; Wyatt et al., 2014), arguably due to the widely debated causal mechanisms, differences in professional and service-user perceptions, lack of treatment guidelines and limited specialist service provision. Within the qualitative research, interactions with medical professionals have been described as 'offensive' and 'disgraceful' (Robson & Lian, 2017). These experiences are hypothesised to relate to negative perceptions that professionals may hold about FND (MacDuffie et al., 2021). This is highlighted in studies comparing how individuals with different diagnoses perceive interactions with medical professionals. Individuals with epilepsy described medical professionals as 'supportive', whereas individuals with functional seizures perceived those involved in their care as 'distrustful' and 'lacking understanding' (Rawlings et al., 2018). Whilst there is a paucity of research exploring the perspectives of those with a diagnosis of FND, research from the perspective of healthcare professionals emphasise the negative perceptions that may be associated with the condition. Some healthcare professionals reported perceptions that FND symptoms were 'voluntary' or 'fake' (Shneker & Elliott, 2008) and that individuals had control over their symptoms (Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsely et al., 2011). It should be noted that these studies were limited to small sample sizes and thus the findings cannot be generalised to all healthcare professionals. However, it could be argued that stigmatised perceptions are influenced by the historical context of FND (e.g., 'hysteria'; Raynor & Baslet, 2021) and gaps in professional's knowledge and training (Hutchinson & Linden, 2021).

These negative interactions in services may be conceptualised as direct enactments of stigma (MacDuffie et al., 2021). Based on Goffman's theory (Goffman, 1963), stigma is considered a process of 'labelling, othering, devaluation and discrimination' (Knaak et al., 2017). This can occur intra-personally (e.g., internalised stigma), interpersonally (e.g., interactions with others) and structurally (e.g., in organisations and systems; Link & Phelan, 2001). In the context of FND, this may be viewed as perceptions of losing personal credibility (Dosanjh et al., 2021), negative experiences of healthcare professionals and lack of investment in specialist service provision and training. There is considerable research highlighting that broader mental health stigma impacts seeking and participating in mental health care (Corrigan et al., 2014). Additionally, a recent systematic review highlighted how individuals may attempt to manage FND stigma by adopting coping styles that inadvertently worsen their condition (e.g., self-isolation; Foley et al., 2022). Although it is acknowledged that individuals with FND experience significant stigma, current research has focused predominately on experiences in medical settings. The impact of stigma on engagement and treatment outcomes has been well-documented across a range of health conditions (Stangl et al., 2019). Although the relationship between FND and stigma has been highlighted (MacDuffie et al., 2021), little is known on whether this impacts the therapeutic encounter in psychological services. Despite individuals with FND regularly accessing psychological services, there is limited published research on individuals' experiences in these settings (Varley et al., 2023). The perspectives of those accessing services are essential in understanding and improving the quality of healthcare provision (Reader et al., 2014). This is particularly pertinent for individuals with FND, with recommendations for future research emphasising that those with a diagnosis of FND should be empowered to share their voices and to drive changes in care (Rommelfanger et al., 2017).

Research aim

The aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with FND.

METHODS

Study design

This study utilised a qualitative approach, with data collected from semi-structured interviews analysed using reflexive thematic analysis (RTA; Braun & Clarke, 2006, 2019). This analysis is compatible with the researchers' epistemological position of critical realism. Critical realism assumes ontological realism; 'the intransitive objects of knowledge are invariant to our knowledge of them' (Bhaskar, 1979, p. 12). Whilst acknowledging epistemic relativism; our measurements are biased, and our understanding tentative and influenced by context (Ponterotto, 2005). Consistent with the epistemological position of critical realism, the generation of themes from the data is influenced and shaped by the researchers' personal and professional contexts (DeForge & Shaw, 2012; Ponterotto, 2005).

The study received ethical approval from the University of Lincoln's Human Ethics Committee (ref: UoL2022_9139).

Participants

Between May 2022 and August 2022, participants ($n = 15$) were recruited via social media platforms and received a £20 high-street voucher following participation. Inclusion criteria stipulated that participants must be aged 18 years or older, be able to speak and comprehend English, have received a diagnosis of Functional neurological disorder from a healthcare professional and have previously accessed support from UK psychological services due to their diagnosis. Support from UK NHS psychological services was defined as a minimum of one session of either individual or group intervention. The rationale for this was to ensure that a range of experiences were captured, including those who had withdrawn from support prior to completion of intervention. Participants were also asked what type of psychological service they had accessed, what professional they had worked with (e.g., psychologist, CBT therapist, mental health nurse) and the type of therapy they had received. However, it was noted that participants frequently reported they did not know what type of therapy or professional they had worked with and due to missing data this information could not be meaningfully compared across the dataset. No exclusion criteria were applied.

Procedure

Participants were provided with the participant information sheet and were required to provide informed consent in writing via post or email. A minimum of 24 h was given between consent and participation in the study. Data were collected using semi-structured interviews and audio recorded using an encrypted Dictaphone. Thirteen interviews were completed via video calling platforms (e.g., Microsoft Teams, Zoom) and two were conducted via telephone. Participants each completed one interview, approximately 30–75 min in duration (average 55 min). The interviews were transcribed verbatim using an automated transcription service prior to data analysis. Transcriptions were checked at least once to ensure veracity prior to data familiarisation and analysis. Interviews were transcribed approximately one week after being conducted to allow time for participants to exercise their right to completely withdraw their data from the study. Participants were informed that they were able to withdraw after this time period, however, data already obtained may have been analysed and therefore may have been unable to be erased.

Analysis

RTA was used to analyse the data collected from the semi-structured interviews. RTA is flexible in its theoretical framework and views researcher subjectivity as a resource during theme development (Braun & Clarke, 2021a, 2021b, 2021c). This study took a mixed deductive–inductive approach with codes generated at both a semantic and latent level to allow for exploration of the meaning associated with individuals' experiences (Braun & Clarke, 2013). This allowed themes to be data-driven whilst also providing an opportunity for exploration of relevant theoretical ideas reflected in the broader literature. Within thematic analysis, themes are considered as organised aspects of the data set that are pertinent to the aims of the proposed study (Braun & Clarke, 2006, 2019). The process of identifying themes begins with the re-reading and familiarisation of transcripts and initial codes are identified. These themes are then reviewed, and a 'thematic map' is produced outlining the super-ordinate and subthemes and the relationships between them (Braun & Clarke, 2006, 2019).

RESULTS

Participant characteristics

Participants were aged between 21 and 54 years old (mean age of 33.66), with 80% ($n = 12$) identifying their gender as female and 20% ($n = 3$) identifying as male. Participants had been diagnosed within the last four years and were all currently accessing psychological services. Further participant demographic information is presented in Table 1. To protect the anonymity of participants, certain demographic information was not included in the final report. Although ethnicity and employment status were collected, neither were indicated as relevant contextual factors in the results and were therefore not included in the journal paper. However, the researcher acknowledged that due to their own ethnic/cultural background (White British), certain nuances relating to this contextual factor may have been missed in the data.

Themes

One superordinate theme and five interrelated main themes were identified. These themes are presented visually in a thematic map (Figure 1).

Superordinate theme: the stigmatised self within the therapeutic relationship

When discussing their experiences of UK psychological services, all participants alluded to the concept of their own self-identity and how this was impacted by their relationships with professionals. The conceptualisation of the self in this relational context highlighted how perceptions of stigma from healthcare professionals may be internalised by the individual. This process appeared to have far-reaching implications on engagement and highlighted the inherent power imbalance within the therapeutic relationship:

> It's difficult to take out those ingrained thoughts and experiences because they've been woven into the tapestry that is my life and it shows how important it is what the message is that professionals are saying because we hold on to them, don't we? And they can maybe impact whether we'd seek support or might just hold us back from seeking support for ourselves when it's really important
>
> Helen

TABLE 1 Sample demographic information.

Participant pseudonym	Age	Gender	No. of months accessing UK psychological services
Amy	41	Female	3 years
Beth	26	Female	2 years
Clara	38	Female	3.5 years
Danielle	30	Female	10 months
Elizabeth	26	Female	2 months
Fran	24	Female	3 months
Grace	23	Female	4 months
Helen	37	Female	1 year
Isla	21	Female	10 months
Joshua	30	Male	2.5 years
Katherine	54	Female	3 years
Liam	49	Male	7 months
Michael	48	Male	2 weeks
Natalie	29	Female	18 months
Olivia	29	Female	16 months

The conceptualisation of FND and the perception of how this was responded to by services and professionals was a central tenet throughout the related themes. These could be considered in the context of reciprocal roles, the relationship between 'doing' and 'done to'; the roles individuals are positioned in or actively adopted, in response to the perceived role that has been adopted by others (e.g., professionals/ services). These reciprocal roles form the expectations of and responses to future interactions (Ryle & Kerr, 2002).

Internalised stigma and self-doubt

The concept of internalised stigma and the self-doubt that this propagated was discussed by all participants. They described the discrepancy between experiencing physical symptoms and being told these symptoms were 'psychological' by professionals. This led to uncertainty about the validity of their own experiences, and subsequently impacted their sense of self. This was reflected in descriptions of self-blame and associated shame. For example, Danielle reported:

> It's like in your head and you kind of start doubting yourself. You kind of start questioning yourself a lot. Am I actually? Is it my fault that I'm having these seizures?
>
> Danielle

These negative views of self and associated ruminations were discussed in the context of internalisations of previous interactions in medical settings. Grace reported, 'to be told that there's nothing wrong with you… it also plants a seed of doubt in your mind then as well'. Specific concerns around 'it all being in my head' and the associated psychological distress were reported by the majority of participants:

> So I've always kind of struggled with that, that feeling that it's all in my head that I know why it's happening, but I still can't get past the fact that I can't control it
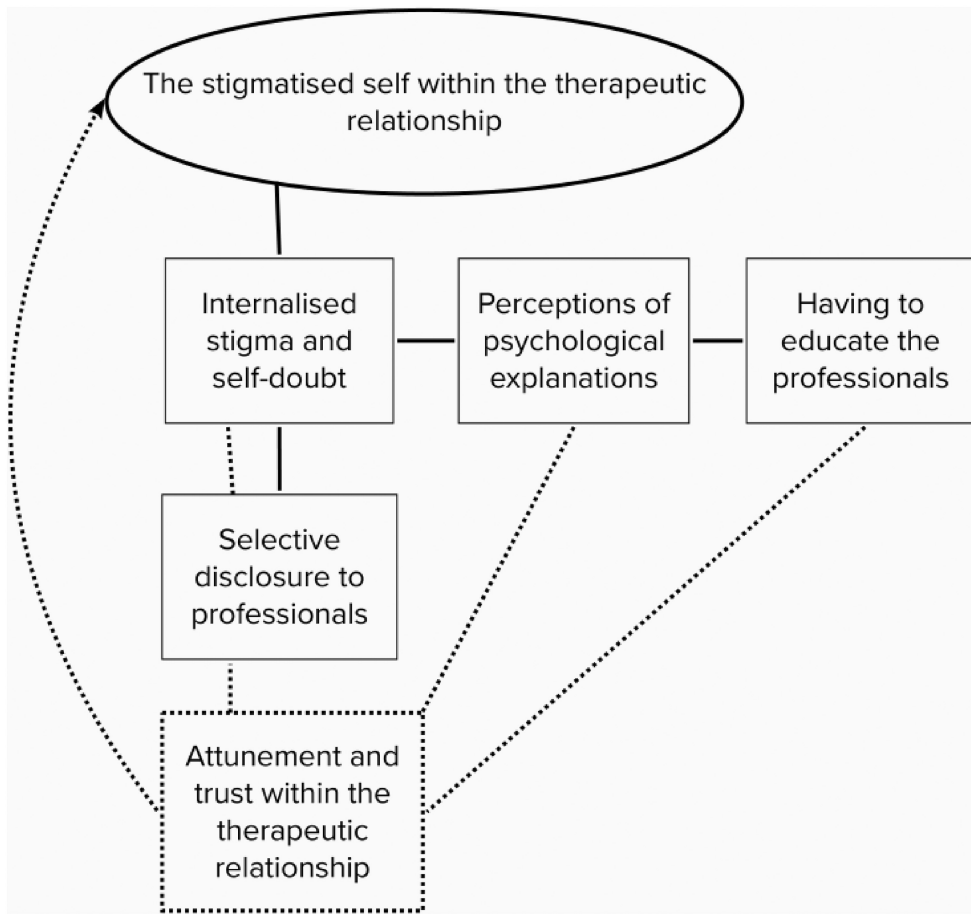>
> Olivia

FIGURE 1 Thematic map.

Although for some participants this appeared to be a re-enactment of externalised stigma from healthcare professionals, others considered the impact of historical social stigma on their views of self. For example, 'you're a mental health patient, it still does have that stigma of you're a fruitcake' [Liam]. Regardless of whether participants reported explicit experiences of stigma in psychological services, internalised stigma appeared to permeate participants' sense of self identity. For example, Beth reported an inner conflict around internalisations of malingering, despite knowing her symptoms were real:

> You know, I know I'm not faking my symptoms but there's always that little voice of doubt in my head that says what if you are? What if you are?
>
> Beth

For most participants, these internalisations appeared to present barriers to accessing and engaging with services. Regardless of participants' perspectives of where the internalised stigma and self-doubt originated, this theme appeared to capture the reciprocal nature of stigma. Furthermore, there was evidence that individual's stigmatised views of self impacted their relationships with professionals in psychological services.

Selective disclosure to professionals

Participants identified a sense of feeling unable to share information with professionals due to a fear of negative judgement:

> 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
>
> <div align="right">Joshua</div>

These anticipated interactions appeared to be framed and experienced through the lens of internalised stigma which manifested as feelings of self-doubt. These internalisations were seemingly underpinned by previous negative experiences of healthcare professionals and the historical stigma associated with FND (e.g., malingering, feigned illness to elicit attention):

> When I first started talking therapy, I didn't talk about all of the symptoms … because I just thought no one's going to believe me. No one's going to believe what it is. I held back certain symptoms or I wouldn't say the whole truth … I think I was just worried that they would think I was making it up and that I was just doing it for attention
>
> <div align="right">Isla</div>

In response to anticipated interpersonal stigma, participants adopted a position of 'being on the defence'. They described withholding information about their personal history based on a belief that some professionals may be unable to contain and integrate this with the professionals' own perspective or understanding. For example, Olivia stated:

> The other thing you kind of realise is that you stopped telling the full story of your life to certain professionals because you know they're just not going to take it
>
> <div align="right">Olivia</div>

Individual differences between professionals were highlighted, with participants reflecting that their levels of disclosure could be influenced by their perception of the professional. For example:

> You categorise professionals a little bit like, well, you're one when I'm not going to speak to completely honestly. You're one that I know I need to not say certain things to you or someone I can speak completely openly with, and because it's like you don't want to hear the lecture
>
> <div align="right">Danielle</div>

The experience of being '*lectured*' and how this impacted disclosure appeared to highlight how individual professionals managed the inherent power imbalance within the therapeutic relationship. One participant described the power professionals held, describing them as 'like God' and reflected on how difficult it felt to challenge a professional as a result of this dynamic. There was a sense of disempowerment shared by several of the participants, with individuals appearing to use selective disclosure as a way of managing their relationships with professionals and avoiding potential conflict.

Perceptions of psychological explanations

Perceptions of psychological explanations was one of the most salient factors influencing all participants' experiences of psychological services. Wariness around psychological explanations appeared to be linked to their levels of disclosure in sessions, with participants describing a worry that aspects of

their life would be seized upon and used as an explanation for their symptoms. Most participants described perceiving these explanations as blaming based on previous experiences of enacted and internalised stigma which became a lens through which psychological formulations were viewed. For example, Katherine reported:

> It felt like they were thinking I'm doing it to myself but the whole time I couldn't understand. Why why why? I can't make it up. This is the thing what I kept saying to them, I can't make it up.

Participants' assumptions about which services they would be referred to based on the physicality of their symptoms appeared to be a complicating factor. This dissonance between anticipating a medical explanation and receiving a psychological formulation was described by several participants as 'difficult to accept':

> It was strange being referred to a psychological service when I've got very, very physical symptoms. It's strange to be told to go to counselling because I can't walk
>
> Grace

Difficulties assimilating their own understanding of the problem with that of the psychological professional's further reinforced these negative perceptions. However, this process was seemingly reciprocal, with one participant highlighting that professionals may also hold rigid preconceptions and have difficulty assimilating a client's contrasting narrative or personal history:

> They kept saying to me things about like psychological triggers, that certain things trigger it, and I could not for the life of me … I could not think of any reason, any logical explanation as to why one minute I could walk and the next minute I couldn't. They were like 'have you been through any stress, any trauma, any like car accident, have you witnessed anything happening like a death or anything?' I was like no, absolutely nothing
>
> Katherine

The idea of trauma and its proposed link to FND was discussed by several participants. Two participants rejected this link but highlighted their perception that professionals were heavily invested in this narrative. Others considered this relevant but acknowledged that this was a difficult explanation to accept and process due to feelings of shame and defectiveness:

> It felt like they were saying my body's reaction to trauma was not to deal with it how a normal person would deal with it, my reaction had been to just shut down
>
> Isla

A barrier to accepting a psychological explanation appeared to be the perception of how their difficulties had been conceptualised by professionals. Whilst links to other mental health difficulties may have been developed as part of the professional's wider formulation, this was perceived as placing the 'fault' within the individual. There was also an implicit aversion to FND being categorised as or compared to mental health conditions, perhaps reflecting experiences of enacted or internalised stigma. However, this also perhaps reflected broader hierarchical views of physical health as 'less stigmatised' compared with mental health conditions:

> Yeah, I did feel not great about it being almost blamed on the anxiety because again, it's sort of comes back to the whole thing of it's your fault, which is the stigma that's attached to loads of mental health issues
>
> Beth

Similarly, different psychological models were considered by some to perpetuate this sense of blame and stigma:

> I think if I'd have had CBT again I might have become quite disillusioned quite quickly. I think CBT aligns with the stigma of FND in a way. I'm a bit sceptical but it feels like it can align itself with some other mental health conditions and that you can just think your way out of it as though it's a logical process
>
> Natalie

However, not all participants perceived the psychological formulation of their difficulties as blaming. Conversely, Michael described feeling 'understood' and 'heard', but acknowledged that this was a sensitive process that required consideration of individual need:

> When I first started, I did not think I was anxious and I think the psychologist realised that, so instead he would say burned out. I suppose using language to engage people… and the pace of it so it's right for the person at that particular time… I think it needs very careful language and I think just gauging the level of what people will understand or want to understand at that time
>
> Michael

This highlighted the importance of professionals 'meeting the [client] where they are' [Michael] and developing psychological formulations collaboratively to minimise individuals' perceptions of blame.

Having to educate the professionals

Some professionals were perceived as lacking knowledge and experience of working with FND and thus the patient found themselves occupying the role of 'educator'. Several participants appeared to have become accepting of this role, 'I think you just have to educate them because they just don't know about FND, by their own admission' [Katherine]. For others, the dynamic between the patient and the professional was not as they had reasonably expected. These blurred boundaries within the therapeutic relationship increased anxiety in those accessing services:

> That makes me very wary because I feel strange being the patient and having to explain what's wrong with me, especially when it's something so complex and I am not fully understanding it myself
>
> Elizabeth

There was an implicit reference that these dynamics with professionals resulted in a loss of trust in services and this had significant implications on individual well-being:

> The more uneducated [professionals] that you meet, the more that affects your FND symptoms and the more you spiral down because you're not getting that support
>
> Beth

This lack of knowledge in services appeared to reinforce perceptions of stigma and the sense of feeling dismissed and doubted by professionals. It was also suggested that participants could experience professionals as 'distancing themselves' from patients with FND. For some this had been perceived as a direct enactment of stigma, for others this had been understood as professionals' own uncertainty and anxiety when working with individuals with FND:

> I've found there's less stigma in mental health services [compared to medical settings] and 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 or what to do with someone with it
>
> Natalie

The perceived responsibility of having to educate the professionals appeared to strengthen narratives around being 'misunderstood' and 'othered' by services. These views of self impacted how individuals related to professionals and perhaps had the potential to impact how professionals related to those accessing services. For example, Katherine reported 'they either don't know what to think about it or what they do know is a very closed view… they don't understand the complexities of it'. An individual's anticipation of these interactions was a barrier to sharing information and contributed to early ruptures in the therapeutic alliance. If not resolved, these ruptures had a significant impact on the development of the professional relationship; 'you don't feel believed, you don't feel supported, you don't feel validated' [Beth].

Attunement and trust within the therapeutic relationship

For all participants, experiences of 'services' were synonymous with the experiences of the interactions they had with professionals. Those that had experienced a positive therapeutic relationship in services described this as having mitigated the impact of other perceived barriers such as anticipations of enacted stigma. Attunement (the process of the therapist being aware of the client's emotional state and responding to this appropriately) was highlighted as a crucial component in developing a sense of safety and trust:

> And I think there's a massive sense of her knowing where I'm at and being able to say the right things at the right time that help me through those difficult moments
>
> Olivia

This attunement appeared to be both explicit and implicit. Psychological explanations of FND communicated from a position of curiosity and compassion facilitated a sense of feeling understood. For example, Michael reported, 'he completely understood me and got me and he said this has occurred for a number of reasons… [you're] not a failure, this is a normal reaction'. Implicit communication within the therapeutic relationship also nurtured a sense of being understood. Natalie explained, '[the psychologist] could read my body language in a way that I can't convey'. The healthcare professional's perceived ability to recognise emotional and physical shifts in the session also appeared to foster trust and a sense of containment:

> There was a moment where I was getting a severe symptom and she could see it even before I could and she could help me, and not many professionals have actually been able to help me. I do have a lot of trust in her
>
> Clara

A positive therapeutic relationship in services appeared to increase participant disclosure and thus the development of a shared perception of the difficulties. This intersubjectivity aided the collaborative process of psychological formulation and arguably lessened the inherent power imbalance between therapist and client. For example, Michael reported '[the psychologist] does it in a very gentle way, but I'm starting to see the patterns with how particular things had happened and I can now say to him, can we think a bit about this?'. This attunement and trust also appeared to support individuals to tolerate and become more accepting of psychological explanations:

I feel like what I've been offered has been brilliant in that it's been factual and useful for me to actually understand what was going on in my body and mind. The one to one session I've been able to dive in to more about me, personally, why certain things might be happening and just the general feeling of like that support and that knowledge, that acknowledgement

Michael

Professionals' knowledge of FND was considered integral to the development of the therapeutic alliance. This appeared to provide a sense of containment for individuals and supported feelings of trust in services. Positive relational experiences with professionals appeared to be internalised, with perceptions of a professional as understanding and accepting challenging an individual's self stigma and negative views of self. Furthermore, a positive therapeutic relationship was described as increasing engagement and future help-seeking behaviours. For example, Isla reported, 'because of that relationship, I would ask for support again if I needed it, just because I'd feel like maybe they could help me too'.

DISCUSSION

This qualitative study aimed to explore the experiences of psychological services from the perspective of those with a diagnosis of FND. One superordinate theme, 'the stigmatised self within the therapeutic relationship', and five interrelated main themes were identified: 'internalised stigma and self-doubt', 'selective disclosure to professionals', 'perceptions of psychological explanations', 'having to educate the professionals' and 'attunement and trust within the therapeutic relationship'.

Experiences of psychological 'services' appeared to be synonymous with experiences of interactions and relationships with professionals. The patterns of interactions between individuals and professionals, referred to as reciprocal roles are underpinned by the 'radically social concept of self' (Ryle & Kerr, 2002). This relational context appeared to impact how participants viewed their own self-identity, with individuals' describing how their sense of self was influenced by the perceived meanings conveyed by others (e.g., professionals; Vygotsky et al., 1978). This highlighted the inherent power dynamic within the patient/professional relationship which appeared to influence participants' levels of disclosure, with selective disclosure used to manage perceived ruptures or conflict. These perceived conflicts were also underpinned by perceptions of, and anticipation of, enacted stigma. The perceived stigma appeared to impact how participants viewed their own self-identity, which is consistent with findings from a recent meta-ethnographic synthesis (Foley et al., 2022). Stigma appeared to function across three levels: intra-personally, interpersonally and structurally (Goffman, 1963; Link & Phelan, 2001). In the intra-personal domain, experiences of perceived stigma appeared to negatively impact how individuals conceptualised themselves and their condition. This appeared particularly pertinent when considering how participants understood their referral to a psychological service. Participants described a sense of 'not being believed', alluded to social stigma around mental health conditions (compared to physical health conditions) and referenced historical stigma associated with medically unexplained presentations, e.g., 'malingering', 'hysteria'. Whilst this study did not explore the perspectives of professionals, the findings are consistent with research exploring medical clinician's negative perceptions of FND (Rommelfanger, 2013; Shneker & Elliott, 2008; Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsely et al., 2011).

Due to the study's qualitative approach, direction of effect regarding stigma and its impact cannot be identified. However, perceptions of stigma in mental health services may be viewed in the context of personal-level barriers (internalised stigma, perceptions of ineffective service) and system-level barriers (lack of FND knowledge and training, service development constraints; Corrigan et al., 2014). The interaction of these perceived barriers were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services. For example, individuals with FND may anticipate stigmatised interactions with healthcare professionals

due to previous negative experiences in these settings and awareness of historical social stigma. In response to this anticipated stigma, individuals may be selective in their disclosure due to mistrust of professionals. It could be suggested that professionals may interpret selective disclosure as 'emotional avoidance', a perception that is widely cited within the wider literature (Raynor & Baslet, 2021). However, consistent with Goffman's theory (1963), enactments of stigma become internalised and impact the conceptualisation of the self. Thus, individuals with FND may find it difficult to accept referrals to psychological services due to experiences of intra-personal (self-stigma) and perceived interpersonal stigma (enacted by others).

These multi-layered experiences of stigma has the potential to impact the therapeutic encounter during the formulation process, with the majority of participants perceiving psychological perspectives as 'blaming'. Whilst proposed links to psychological trauma were accepted by all but two of the participants, it was highlighted that individuals held narrow views of what constituted psychological trauma. This is perhaps due to understandings of trauma being based on specific diagnostic criterion (DSM-5; American Psychiatric Association [APA], 2013; ICD-11; World Health Organisation [WHO], 2019), rather than broader psychological theories on experiences that impact the autonomic nervous system (Porges, 2007, 2009). Regardless of participants' perspectives on trauma and its proposed link to FND, there was an acknowledgment that this needed to be communicated sensitively, as to not reinforce ideas of 'fault'. Some participants referenced the importance of adopting the client's language to support engagement and overcome resistance. This is consistent with conversational analysis studies that have found mirroring of client language can facilitate a shared understanding of client experiences and presenting difficulties (Knol et al., 2020). Furthermore, language style matching by the therapist has been found to increase perceptions of empathy (Lord et al., 2014) and foster development of the therapeutic alliance with clients who may be hypervigilant to rejection (Borelli et al., 2019). This appears to be particularly important for individuals with FND who may anticipate rejection and dismissal from healthcare professionals due to multi-layered stigma.

The perception that professionals lacked knowledge about FND was consistent with previous research that concluded that medical professionals did not feel adequately trained with FND-type presentations (Hutchinson & Linden, 2021). Although, it should be noted that this research did not consider the perspectives of other healthcare professionals and thus cannot be generalised across disciplines. Despite this, some participants acknowledged that whilst there was less explicit stigma in psychological services (compared with medical settings), there was a perception of professionals 'distancing themselves'. Whilst this study did not explore perspectives of professionals, findings from a recent meta-synthesis identified that professionals may be anxious of 'saying the wrong thing', 'offending patients' and thus avoid patients with FND (Barnett et al., 2022). These findings are strikingly similar to conclusions drawn from a systemic review of professionals' experiences of working with psychogenic non-epileptic seizures (Rawlings & Reuber, 2018), suggesting that uncertainty around causal and maintaining factors of presentations may influence these patient/professional relational patterns. These perceptions of enacted stigma may also be viewed through the lens of organisational stigma (Goffman, 1963). The lack of specialist provision for FND results in individuals accessing general mental health services that are not resourced to meet their needs. This may highlight more fundamental issues regarding the false mind–body dualism that underpins service provision, e.g., the separation of physical and mental health services. When considering the relational impact of this, participants described that 'having to educate the professional' led to the dynamic between patient and professional not being as they had reasonably expected, blurring the boundaries of the therapeutic relationship.

The process between relating to others, how others related to individuals and how individuals related to themselves was a central tenet throughout the themes. This emphasised the therapeutic relationship as a key component to positive and helpful experiences of services. Those that had experienced a positive therapeutic relationship in services described that this had mitigated the impact of other perceived barriers and had the potential to increase future help-seeking behaviours. These qualitative findings were consistent with previous research in medical settings that highlighted the integral role of the therapeutic relationship on outcomes for those with a diagnosis of FND (Hutchinson & Linden, 2021).

These findings are also consistent within the wider literature on the link between the therapeutic relationship, engagement and clinical outcomes (Horvath & Symonds, 1991; Klein et al., 2003). In the context of stigma and its impact on the therapeutic encounter, participants referenced that the therapeutic relationship had the potential to revise internalisations of enacted stigma and thus improve engagement with psychological services.

Strengths and limitations

This research was the first qualitative study to explore how individuals with a diagnosis of FND experience psychological services in the UK and highlighted how perceived stigma impacts the therapeutic encounter. Furthermore, the study also addresses aims of a recent research agenda (MacDuffie et al., 2021) and provides a basis for understanding how perceived stigma impacts how individuals with FND conceptualise themselves and the condition. However, the research findings must be considered in light of several methodological limitations. Recruitment via social media may have inadvertently introduced bias within the sample. For example, individuals who are less likely to be on social media (e.g., the older population) may be less represented in the sample. Due to the nature of the qualitative approach, the findings of this study cannot be generalised to the wider population. However, despite the small sample size, the sample was potentially representative of the FND population in terms of gender ratio and varied age of onset (Lidstone, Costa-Parke, Robinson, Ercoli, & Stone, 2022). Although the focus of the study was limited to UK psychological provision, there was a range of diversity in the localities of participants, and thus experiences were not solely reflective of one service or NHS Trust. However, it is acknowledged that participants frequently reported they did not know what type of therapy or professional they had worked with and due to missing data this information could not be meaningfully compared across the dataset. Further research is needed to ascertain whether type of service and treatment modality impacts individuals' experiences.

Whilst the study provided rich data on the experiences of individuals with FND, it does not consider how this may compare to other stakeholder perspectives (e.g., therapists, clinical psychologists, mental health practitioners). Within the wider literature, there is research exploring medical professionals' perspectives, however it remains unclear how psychological practitioners experience this therapeutic encounter. Future qualitative research is needed to understand these perspectives, specifically the barriers and facilitators to engagement and to the development of the therapeutic relationship. Given the higher prevalence of women diagnosed with FND and existing research highlighting impacts of gender-based stigma in healthcare (Appignanesi, 2011), further research should also consider intersectional stigma and FND (MacDuffie et al., 2021).

Clinical recommendations

Professionals should be mindful of how experiences of stigma may impact an individual's perception of explanations pertaining to FND. This should be considered when referring individuals to psychological services through to formulation and intervention. It should be explicitly discussed that 'psychological factors' are not synonymous with faked symptoms, with reference made to the biopsychosocial framework (Brown, 2007; Engel, 1977). Similarly, whilst psychological formulation should be tailored to the individual and integrative in its approach, theories that bridge the gap between the mind–body dualism may be helpful to reduce feelings of shame, e.g., Polyvagal Theory (Porges, 2007), the impact of psychological trauma on the autonomic nervous system (Sherin & Nemeroff, 2011), Bayesian Inference Model (Edwards et al., 2012). Practitioners should be mindful that any specific event/experience or explanatory model is likely to be insufficient in explaining the onset of FND, and therefore, the formulation should be held tentatively. Psychological formulations should be paced appropriately as to not overwhelm the client (Dawson & Moghaddam, 2016) with

language style matching used to support a shared understanding (Knol et al., 2020). When considering the impact of enacted and internalised stigma, the formulation process may be particularly important in fostering feelings of validation, acceptance, and compassion. Furthermore, practitioners should explicitly address perceptions of blame and provide psychoeducation on the impact of living with a chronic condition and/or coping responses to trauma/stressors and the impact of this on the nervous system. Within the wider literature, high levels of shame have been linked to functional neurological presentations (Reuber et al., 2022) with recent research emphasising the importance of the therapeutic relationship in revising negative beliefs of self that may be held by those with a diagnosis of FND (Myers et al., 2022). Experiences of stigma and how this may influence perceptions of psychological models (e.g., CBT) should also be considered. Given organisational constraints such as the limited specialist FND services (Walker, 2019), psychological services and clinical training providers may benefit from increasing training provision for clinicians. The findings of this study suggest that training for practitioners should aim to develop knowledge and awareness of FND, with consideration of how stigma may impact the therapeutic relationship. This training should be co-produced and co-delivered with experts by experience, to minimise the risk of stigmatised ideas being further embedded in services. It is recommended that this training is evaluated from multiple perspectives, with a focus on the impact on clinical practice.

CONCLUSION

To our knowledge, this is the first study exploring the experiences of psychological services and highlights the impact of perceived stigma on the therapeutic encounter from the perspective of those with a diagnosis of FND. Our findings provide a nuanced understanding of how intra-personal, interpersonal, and organisational stigma impact access and engagement to psychological treatment. These findings were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services. Positive therapeutic relationships were perceived to mitigate the impact of perceived barriers. Furthermore, the therapeutic alliance may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention. The findings of this study are a call to action for practitioners to actively challenge FND stigma within services, at both an individual and systemic level.

CONFLICT OF INTEREST STATEMENT
The authors have no conflicts of interest to declare. All co-authors have seen and agree with the contents of the manuscript, and there is no financial interest to report.

DATA AVAILABILITY STATEMENT
The data that support these findings contain identifiable information and, to protect the confidentiality of participants, have not been made openly available.

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