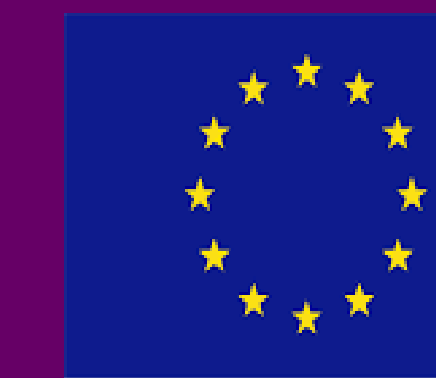


How Stigma unfolds for Patients with Functional Neurological Disorder



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Stigma is a multi-factorial, social process, that can occur interpersonally and structurally. It includes components such as;

labelling, stereotyping, separation, status loss and discrimination (Link & Phelan, 2001)

Stigma in FND - what is known already?

- Though recognition of FND as a valid and treatable disorder is growing, it remains a **neglected condition**, influenced by outdated misperceptions and unhelpful attitudes.
- A 2020 survey of 503 participants run by the charity FNDHope, showed that **81.6% felt they had been treated poorly due to stigma**.
- Quantitative studies show stigmatisation is around **40% more likely** for patients with functional seizures than epilepsy.
- Stigma with functional seizures is associated with poorer overall **quality of life**, health-related quality of life, perception of **self-control** and **caregiver burden**.

Why carry out this study?

- Although some qualitative studies have examined patient experiences/perspectives of FND from which stigma themes naturally emerged, most did not aim to explore stigma specifically.
- Most existing stigma studies relate to functional seizures – not covering the fuller spectrum of FND symptoms.
- More in-depth knowledge about the development of stigma in FND could direct the formation of **“anti-stigma” interventions** and potentially improve outcomes for this group.

Aim

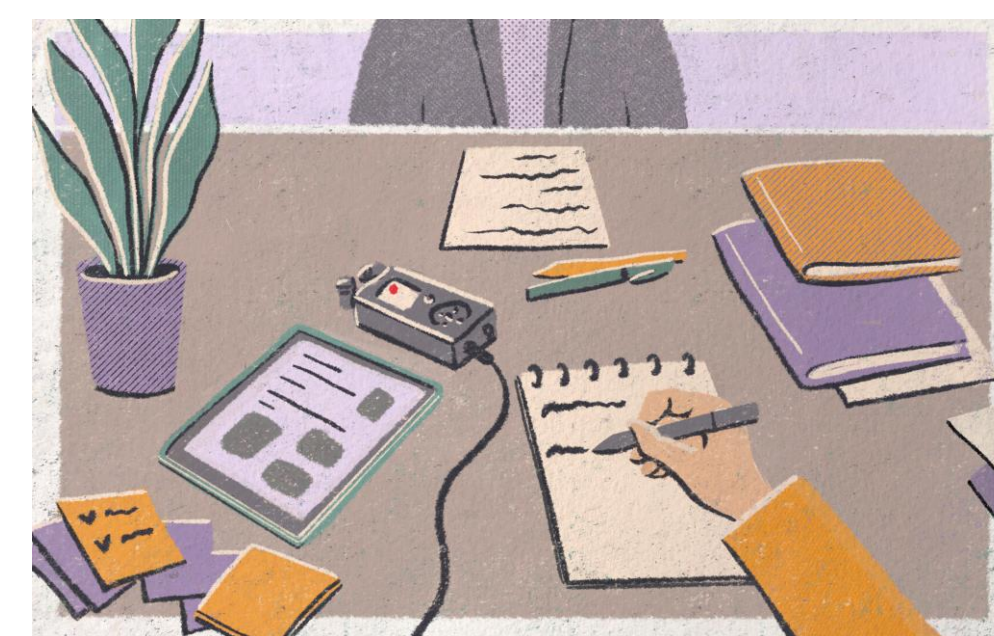
Therefore, while it is clear that stigma exists in FND, it is less clear where stigma originates from, how it unfolds, and how it can be alleviated.

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.

Method

Design

This is a qualitative study, using data from semi-structured interviews with adults diagnosed with FND, recruited from neurology clinics.

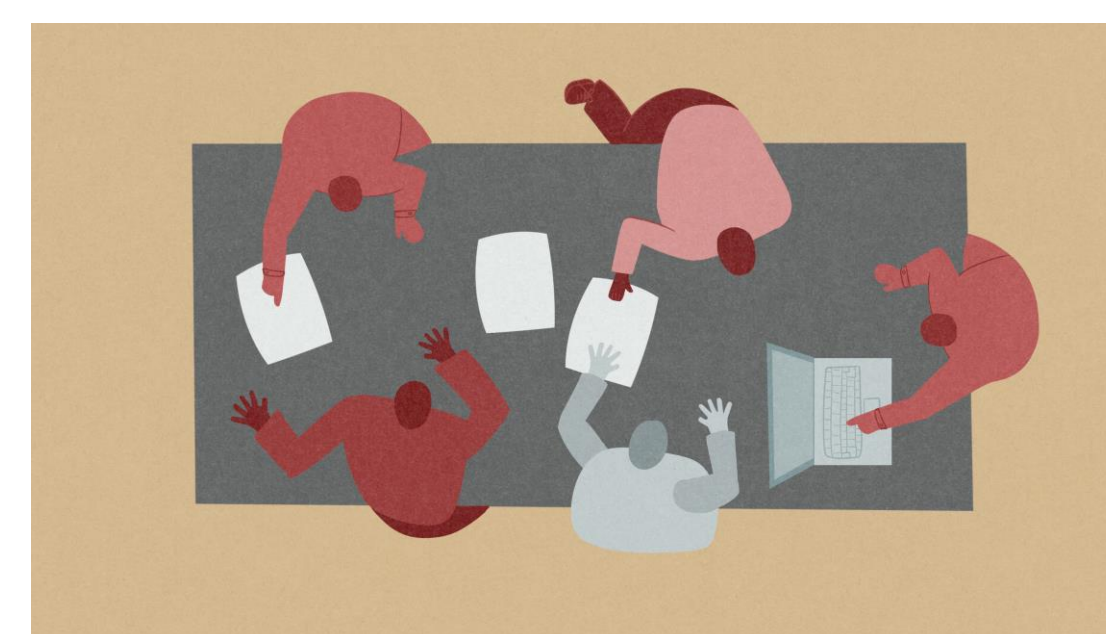


Participants

- We wanted a range of stigma-related experiences. We employed purposive sampling to ensure diversity in age, gender, symptom presentation, and diagnosing clinician.

Interview procedure

- All interviews were audio-recorded and transcribed verbatim.
- Our discussion guide was informed by the various stigma frameworks as described in the sociological and healthcare stigma literature.
- We chose open questions about patient experience as not to be leading, deliberately not mentioning stigma, giving space for both positive and negative experiences.



Analysis

- We analysed the data using a **reflexive thematic analysis** approach, which involves the generation of codes, themes and subthemes relevant to our research question.
- To reduce the risk of bias, we strived to remain cognisant and reflective about existing assumptions from our clinical and research experience.
- We held regular consensus/discussion meetings between the authors regarding emerging patterns of codes, themes and subthemes.

Results

- 15 participants, aged 19 to 68 years, 11 female, 1 non-binary, 3 male.
- Full spectrum FND symptoms (including visual/cognitive symptoms).
- Six themes and 16 subthemes.

Theme/Subtheme	Illustrative quote
FND symptom experience	"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
a) Visibility of symptoms	"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
b) Invisible	"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 I spent days in the hospital coming to terms with" - Sam
c) Voluntary control	
“Othered” by health system	"the experience with the GPs hasn't been very...ehm...and it actually upset me quite a fair bit...he did say...could you not walk in and I'm like I cannae" - Grace
a) Healthcare professional attitudes	"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
b) Point of diagnosis	"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
c) Functional is left out and “lesser”	
Everyday interactions	"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
a) Friends and family	"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..." - Hailey
b) Work	"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
c) Online	
Self	"I feel like a useless piece of ... flesh that doesn't work properly" - Una
a) Devaluation	"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
b) Shame	
c) Strength	"I've learnt a lot through the process, I think probably ehm value myself more" - Orla
Stages of knowledge	"I've been going back and forward to the doctor with but nobody knew what was wrong ... 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
a) Misperceptions	"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
b) Importance of explanations	
Validation of patient experience	"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
a) Within professional 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
b) Within wider context	

Table 1. Main themes and subthemes with illustrative quotes

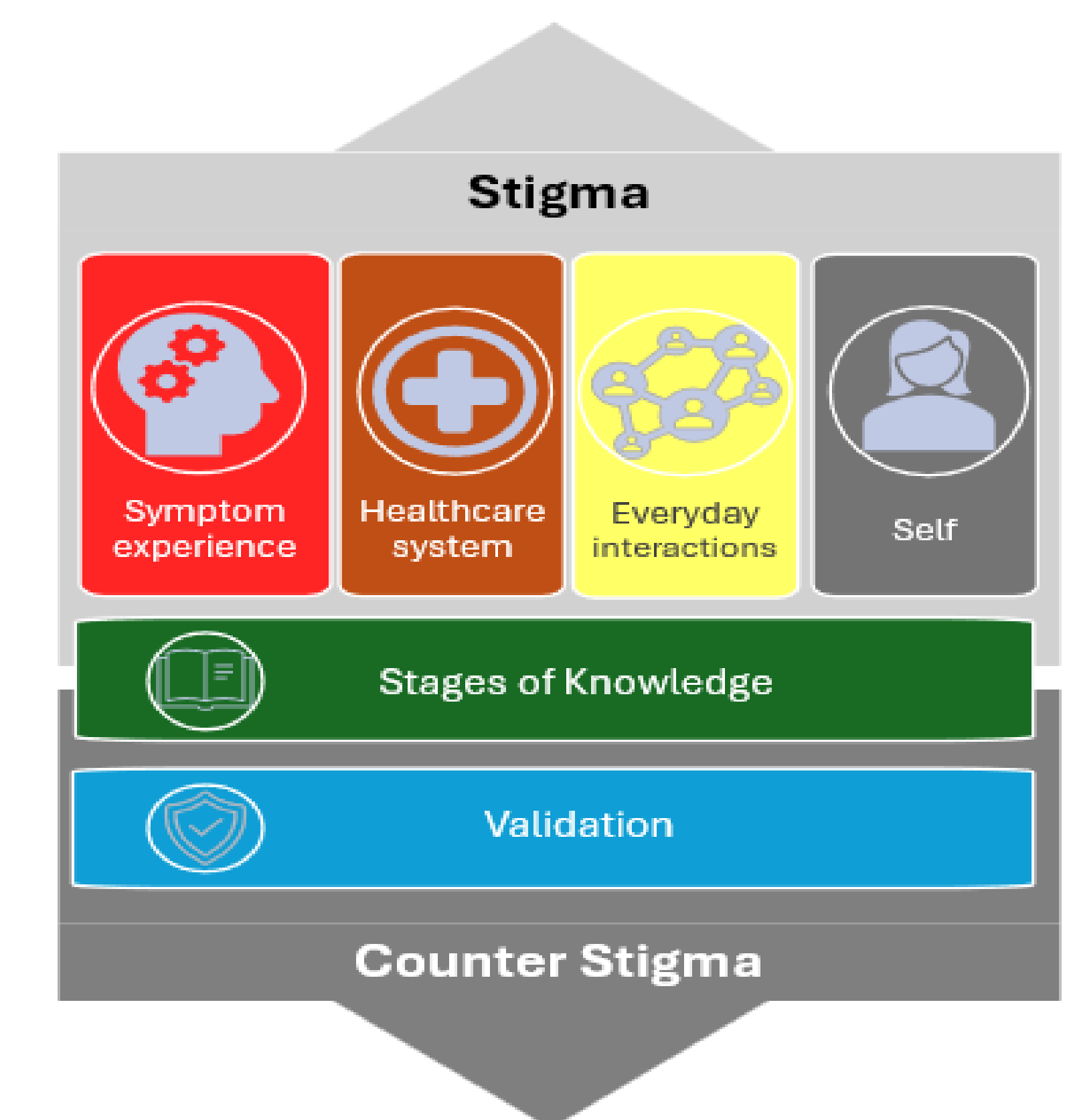


Figure 1: The patient experience of stigma did not unfold as a linear trajectory. Rather, six key themes dynamically interacted with each other. Stigma unfolded through 1) their **symptom experience**; 2) through **“othering” by the healthcare system**; 3) through **everyday interactions** with friends, family, colleagues and online; 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 stigma.

Conclusions

- Stigma unfolds as a layered process, influenced by surrounding structures, relationships, what is held internally and what has gone on before.
- Given how stigma occurs as a cyclical process, it is likely that addressing one key area might impact another.
- Interventions to target stigma could focus on improved clinician training, including the core and “hidden” curricula, and clinical communication.
- It might be helpful to be aware of sources of stigma and explain specific aspects of FND that might contribute - for example, the variability/distractibility inherent in FND could be explained so people understand why the symptoms are not always constant or visible.
- Patients could be advised about the risk of encountering online misperceptions, and future studies could assess the accuracy of online information and perceptions of FND in the public domain.
- Educational and anti-stigma interventions should be co-delivered and co-produced with patients with FND.

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