Illness perceptions, stigma and engagement in Functional Neurological Disorder (FND): exploring the role of multidisciplinary group education

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Introduction

People with FND report limited understanding of their condition (Ludwig et al., 2015), poor quality of life (Anderson et al., 2007) and high levels of stigma (Foley et al., 2022).

A critical first step in managing FND is a positive diagnosis and clear explanation using an understandable illness model (NNAG, 2023; Stone, 2016). Multidisciplinary group education sessions are one way to contribute to this, and there is some evidence they improve understanding, confidence in diagnosis (Cope et al., 2020) and outcomes with further treatment (Stenberg et al., 2016). In many conditions, including FND, illness perceptions and stigma affect distress, functioning, quality of life and treatment engagement (Williams et al., 2023). Exploring relationships between these factors could generate deeper understanding of the impacts of educational interventions on outcomes.

A multidisciplinary (MDT), cognitive behavioural therapy (CBT) informed FND group education session has been run by the neuropsychiatry service at St. George's Hospital, London since 2016. FND group education sessions could be a cost-effective addition to FND pathways but their impact on outcomes and illness perceptions has not been studied.

Aim

We sought to examine illness perceptions in education session attendees and relationships with comorbidities, quality of life and experiences of stigma. A secondary aim was to consider how education might influence illness perceptions and engagement.

Education Session

The 1 hour: 45 minute session includes presentations from 4 MDT members (neurologist, neuropsychiatrist, psychologist, neurophysiotherapist) and expert by experience. Sessions attract approximately 50 attendees with FND (plus carer/family members) every 3 months. Topics covered include assessment, diagnosis, common symptoms, aetiology and treatments. Two fictional FND subtype scenarios illustrate biopsychosocial CBT formulations. There are opportunities to ask questions and summary handouts are given containing links to online educational, self-help and peer support resources. Additional information can be found in previous papers (Cope et al., 2020; Stanton et al., 2023).

Method

All patients referred to St George's Hospital Neuropsychiatry service with established FND diagnosis were eligible for inclusion if over 18 years old, able to consent and fluent in English. Interested participants completed online consent forms and baseline surveys before the session, immediately after and 1 month later.

The study was developed with input from FND Hope scientific committee who helped design sensitive questions about "beliefs" and "illness perceptions" in the context of many individuals having their experiences dismissed or disbelieved. NHS ethical approval awarded from the HRA and HCRW (IRAS ID:26833).

Measures

Self-reported symptoms: primary FND and other symptoms
Revised Illness Perceptions Questionnaire (IPQ-R): An 84 item measure based on Leventhal's 'common sense model of self-regulation'
Scale for Stigma in Chronic Illness (SSCI-8): Measures both enacted and internalised stigma
Chronic Illness Anticipated Stigma Scale (CIASS): Measures anticipated stigma; a person's expectations of prejudice, stereotyping and discrimination
Patient Health Engagement scale (PHE): Assesses engagement and is validated in fibromyalgia and rheumatoid arthritis
Short Form 36 (SF-36): Assesses disability via eight health concepts exploring limitations in functioning, role, sense of vitality and pain
Hospital Anxiety & Depression Scale (HADS): Depression and anxiety screen

All measures were collected at baseline but only IPQ-R, PHE, SSCI-8 and CIASS repeated immediately and one month. A free text box asked participants what questions they had about their FND at the three time points and what help or support they needed.

Analyses

SPSS was used to analyse quantitative data. Missing data was handled using Little's MCAR and independent sample t-tests for those who did and didn't complete follow up. Spearman's correlation coefficients investigated relationships between illness perceptions and mood, quality of life, and stigma. Repeated-measure ANOVAs with Bonferroni corrections assessed differences between timepoints. Content analysis using NVIVO was employed for qualitative data.

Results

Out of 166 people attending sessions between January 2022 and July 2023 61 patients with FND completed baseline assessments, 33 (54%) completed 1 month follow up.

Participants were aged 18 – 72 (mean 47.8), and majority women (72.1%), White-British (68.9%) and not in full time work (78.3%), with 24.6% on long-term sick leave. Fatigue was the most common comorbid symptom (72.1%), followed by memory or thinking problems (70.5%) and anxiety (68.9%).

Primary FND symptom	**N**	**%**
Movement disorder	8	13.1
Gait disturbance	8	13.1
Tremor	3	4.9
Weakness or paralysis	9	14.8
Muscle dystonia	5	8.2
Seizures or fits	15	24.6
Memory or thinking problems	5	8.2
Numbness or tingling	3	4.9
Other (dissociation, fatigue, speech)	5	8.2
Duration of symptoms	**N**	**%**
3-6 months	3	4.9
6-12 months	14	23.0
1-5 years	27	44.3
More than 5 years	17	27.8

Figure 1: Baseline symptom types and duration

Patients reported poor quality of life, functioning and high levels of stigma. Illness perception scores indicated FND as threatening, mysterious and unpredictable, with low personal or treatment control over symptoms.

Illness coherence/understanding (20.9% mean change, mean difference 2.27 p<0.01, 95% CI: 1.22-4.23) and engagement (14% mean change, mean difference 2.42 p<0.01, 95% CI: 0.46-4.36) scores increased after the session.

Higher stigma scores on SSCI-8 (0.52 CI: 0.31 – 0.67 p<0.001) and CIASS (0.450 CI: 0.217 – 0.635 p<0.001) were associated with lower social functioning (measured with SF-36) in 59 participants at baseline. Higher stigma on SSCI-8 (0.55 CI: 0.33-0.71 p<0.001) and anticipated stigma from colleagues was associated with higher scores on HADS depression scales (0.54 CI: 0.32-0.70 p<0.001).

Self-reported needs (*figure 2*) highlighted the importance of personalised formulation, practical advice on living with disability, help with explaining the condition to others (e.g. employers), and accessing peer support and treatment.

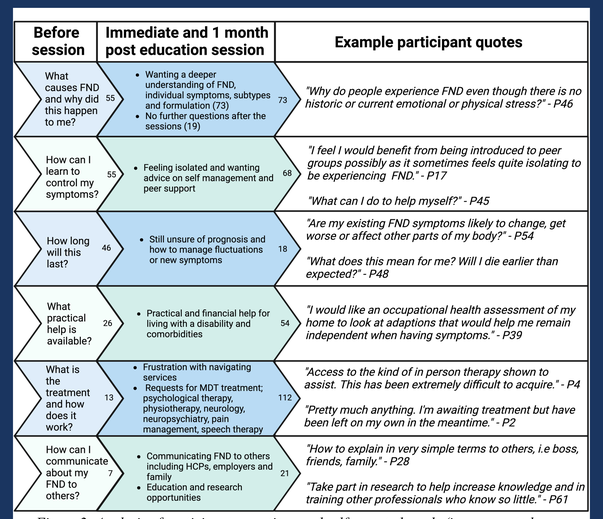

Figure 2: Analysis of participants questions and self-reported needs (image created with BioRender)

Conclusions

Illness perceptions in FND should be conceptualised as being in dynamic relation with experiences of stigma, social and occupational functioning and challenges in accessing services. Interventions which address stigma and discrimination towards people with FND in health systems and work environments should be a focus of future research. Multidisciplinary group FND education sessions potentially improve patient understanding and engagement. Clinicians should consider the possible benefits of personalised formulations and linking to practical and peer support.

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