

Experiences, understanding and conceptual models in patients with functional neurological disorders: a qualitative and quantitative study

Dr Cate Bailey

MD (Res) MHRUK Scholarship 2019: King's College London

Supervisors: Dr Timothy Nicholson, Dr Norman Poole, Professor Thomas Craig, Dr Virginia Eatough

St George's Healthcare 
NHS Trust

KING'S
College
LONDON

INTRODUCTION AND AIMS:

Functional neurological disorders (FNDs) occur when a person develops symptoms (such as weakness, numbness, tremors or seizures) which are not caused by neurological disease but have distinct clinical features. The symptoms can appear similar to epilepsy, multiple sclerosis or Parkinson's disease. However, in FNDs the structure of the nervous system is normal but there is a problem with how the brain and nerves are functioning.

The primary aim of this study is to explore the lived experience, understanding and conceptualisation of the illness, engagement and needs of people with FND. A secondary aim is to investigate the experiences of people with FND who attend a novel multi-disciplinary psychoeducation session. The study is exploratory and hypothesis generating.

BACKGROUND:

FNDs are as common as Multiple Sclerosis (1); accounting for somewhere between 6-16% of neurology outpatient consultations (2). Despite their frequency FNDs remain poorly understood, are associated with significant stigma and disability and patients often experience consultations with doctors as confusing and the explanations given unhelpful (3,4). Those with functional seizures or functional weakness both describe a low level of personal control and understanding of their conditions, often feeling that their illness is a mystery and will be permanent (5).

Although there have been rapidly increasing amounts of imaging studies in functional weakness and tremor, there is very little research exploring patient experience (6-8). A recent study found patients were dissatisfied with the explanations they had received, felt powerless and abandoned by clinicians and services (8). However, studies of patients with functional motor symptoms have also found that early diagnosis and high satisfaction with care were associated with positive outcome (9). As in many other conditions the explanation given by the doctor, and the patient's understanding of FND will affect engagement and confidence in treatment (11).

In the last ten years research describing the interaction between nervous system functioning, prior expectations and sensory evidence mediated by abnormal attention and emotion has provided a unifying explanatory model (10). In keeping with emerging evidence that explanation and validation of the disorders can be therapeutic, clinicians who work with these patients are engaging them in the diagnostic process and demonstrating the potential for reversibility and treatment (11). This model informs the approach at St George's Functional Neurological Disorders service, from which participants will be recruited. Part of the treatment is a 2-hour didactic psychoeducation session for patients and their family. This includes lectures from an experienced neurologist, neuropsychiatrist, psychologist, neuro-physiotherapist, and patient-expert.

METHODS AND STUDY PLAN:

1) **Scoping review** of the literature exploring patient, family and public perceptions, explanations and experiences of functional weakness or movement disorders.

2) **Systematic review** of the literature exploring health care professionals' experiences and explanations of functional weakness or movement disorders.

3) **Quantitative study** of illness understanding, engagement, comorbidities, quality of life, functioning and experiences of stigma in patients attending a novel psychoeducation session for FNDs collected electronically via RedCap (a secure online data platform). Data on illness understanding, stigma and engagement will be collected pre and post the psychoeducation session, and 1 month later to better characterise illness burden and comorbidities in the group and to assess if the intervention affects patient understanding of these disorders.

90 participants

4) **Qualitative exploration** of the experiences of patients with functional weakness or movement disorders and their experiences of attending the psychoeducation session explored through focus groups.

2 focus groups
(6-8
participants)

5) **Qualitative exploration** of the lived experience of patients with functional weakness or movement disorders who have yet to attend the psychoeducation session through in-depth individual interviews. Topics considered will include the meaning of symptoms, conceptual models, experience of agency, awareness of attention and understanding of diagnosis. The interviews will be analysed using interpretative phenomenological analysis (IPA) (12).

4-6 individual
interviews

PROGRESS:

Since commencing the MD study in June 2019 a draft protocol has been completed including selection of outcome measures. Funding for participant fees and travel has been granted by the Psychiatry Research Trust. Engagement and consultation with the organisation FND Hope has resulted in ongoing considerations regarding patients' conceptualisation of the disorders and honing the focus of the work on lived experience. Of particular note are discussions on the approach to researching illness concerns and understanding, and the acceptability of particular terms and instruments for measuring experiences and beliefs. Work has commenced in framing the research question and search strategy for the systematic and scoping reviews.

FUTURE PLANS:

A revised study plan will again be discussed with FND Hope with the aim of then applying for ethics approval by April 2020. It is anticipated that recruitment for quantitative arm of the study will commence in Summer 2020. Consultation on the scoping and systematic review will commence once the ethics application has been submitted, with searching and abstract selecting planned to begin in May 2020.

Dissemination and outcomes will include papers published in peer reviewed journals, conference presentations, feedback to St George's hospital staff and service users, and other avenues to be discussed with FND Hope.

CONTACT:

cate.bailey@nhs.net
@_parapraxis_

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