

A service evaluation of the experience of patients with Functional Neurological Disorders within the NHS

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Introduction

Functional Neurological Disorders (FNDs) are a spectrum of long-term neurological conditions (LTNCs) that are not explained by organic disease. Previous research has shown that there are significant barriers in providing multidisciplinary, patient-centred care for FND (1). These include stigmatising attitudes, poor knowledge about FND, and a lack of structured care pathways.

The National Service Framework for Long Term Conditions (NSF) was published to improve the quality of care for patients with LTNCs (2). It set out 11 quality requirements relating to the diagnosis and care of LTNCs, providing standards against which the care of LTNCs can be measured. Peters et al (3) developed a patient-reported questionnaire to measure LTNC patients’ experiences of problems in their care, based on the NSF quality requirements.

To date, there has been no research into patients’ experiences of care for FND within NHS healthcare services and how these compare to the quality standards of the NSF.

Aim

The objective was to compare the experience of FND patients to patients with Multiple Sclerosis (MS) to explore whether there was a difference in the frequency and types of problems experienced between the two patient groups, using the questionnaire developed by Peters et al (3).

It was predicted that FND patients would report a higher frequency of problems in all domains.

Method

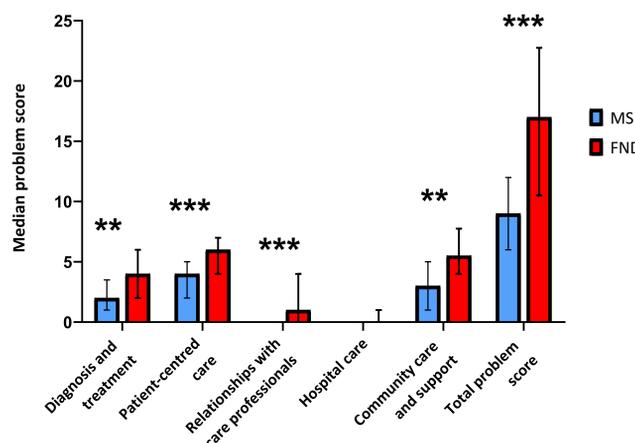
77 patients (40 FND and 37 MS) were recruited prospectively and sequentially from a tertiary neurology service at a London NHS hospital. These patients were new attendees to the clinic and completed the relevant questionnaires prior to attending their first consultation.

Two questionnaires were used:

- The Experience of Health and Social Care Questionnaire (3) – self-report questionnaire on LTNCs patients’ experiences of healthcare in the past 12 months.
- 5-level EQ-5D (EQ-5D-5L) – standardised self-report tool to measure quality of life and general health, collected as part of routine clinical practice.

Responses on these questionnaires were re-coded into ‘problem’ scores and were compared across patient groups. Summary problem scores for each domain and in total were also calculated.

Results



Median problem scores for each patient group across all domains and in total. Error bars represent the upper and lower quartiles of the median. Asterisks denote a significant difference in medians between the patient groups at the $p < 0.050$ level.

There were significant differences between FND and MS patients in all domains, except hospital care. Post-hoc tests showed problems experienced significantly more by FND patients in each domain:

Diagnosis and Treatment	<ul style="list-style-type: none"> • Waiting over 6 months to see a specialist • Waiting over 12 months to receive a definite diagnosis • Receiving insufficient information of medication side effects
Patient-Centred Care	<ul style="list-style-type: none"> • Experiencing difficulty in seeing a healthcare professional in past year • Had not attended a specialist clinic in past year • Poor coordination between care services in planning care • Not feeling involved in care decisions • Not feeling wishes and preferences about their care were taken into account
Relationships with Care Professionals	<ul style="list-style-type: none"> • Feeling their needs were not understood and they were not treated with respect and dignity by consultants, GPs, and other healthcare professionals in hospital
Community Care and Support	<ul style="list-style-type: none"> • Feeling their personal finances were affected to a larger extent • Not receiving respite care that is needed

MS patients reported significantly more issues in accessing financial support.

FND patients were significantly more impaired on almost all domains of the EQ-5D-5L, but were not significantly different to MS patients on the anxiety/depression domain.

Discussion

4 main themes of problems experienced by FND patients were identified within the results:

Delayed and poor communication in diagnosis and treatment

Poor relationships with healthcare professionals

Difficulties in accessing services and support

Burden of illness/care

Significant issues in their care were reported more frequently by FND patients, despite presenting with similar levels of disability as MS patients. These problems are significant as they may impact both the prognosis and burden of illness experienced by patients. The greater frequency of problems reported by FND patients may be explained by healthcare professionals’ negative perceptions of FND, stigma experienced by patients, and a lack of structured, coordinated care.

Limitations

- Small sample size
- Specificity to a single neurology clinic
- Cross-sectional design

Larger samples across multiple sites over time comparing FND to other neurological conditions are needed.

Conclusion

Current care for FND patients is not meeting quality standards set out by the NSF, with key problems in patient-centred care and delayed diagnosis and treatment. There is a need for further research using patient-reported outcomes and the development of structured, multidisciplinary care pathways that adopt a patient-centred approach.

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