What are the experiences of people with motor and/or sensory functional neurological disorder?

A systematic review and thematic synthesis of qualitative studies

Cate Bailey [1,2], Arnas Tamasauskas[3], Abigail Bradley-Westguard[1], FND Portal[4], Norman Poole[5], Mark J. Edwards[1], Niruj Agrawal[6,7], Timothy R Nicholson[1]

1. Neuropsychiatry Research and Education Group, Institute of Psychiatry Psychology & Neuroscience, King's College London, UK.
2. East London NHS Foundation Trust, London, UK.
3. Liverpool Brain Lab, University of Liverpool
4. FND Portal https://fndportal.org/
5. Lishman Unit (Brain Injury and Functional Neurology), South London and Maudsley NHS Foundation Trust, London, UK
6. Neuropsychiatry Service, South West London & St. George's Mental Health Trust, St. George's Hospital, London, UK.
7. Atkinson Morley Regional Neurosciences Centre, St George's University Hospital, London, UK.

Contact: Cate Bailey
Email: cate.bailey@nhs.net
Twitter: @_parapraxis_

Introduction

Functional neurological disorders are common (Carson & Lehn, 2016), highly stigmatised (FND Hope, 2021) and associated with significant disability (Carson et al., 2011; Gelauff et al., 2014). A systematic review of the experiences of people with functional seizures described negative interactions with healthcare professionals and a significant burden of living with seizures (Rawlings & Reuber, 2016). A synthesis of the views and experiences of healthcare professionals working with people with FND found that many felt unsure how to diagnose and treat FND and tended to avoid and pass patients on, leading to a 'vicious cycle' where patients receive poor care (Barnett et al., 2022).

Motor FND includes symptoms such as paralysis or weakness, gait disorders, tremor, myoclonus, tics (jerky movements) and dystonia (Perez et al., 2021). Functional sensory symptoms include altered or absent sensation in the affected area (Stone et al., 2003). Although sensory disorders commonly co-occur with weakness or movement disorders, they are relatively less studied (Stone et al., 2003). Functional communication, swallowing and cough disorders (Baker et al., 2021), drop attacks (Hoeritzauer et al., 2018) and functional forms of dizziness (Dieterich & Staab, 2017) affect sensory or motor function and are increasingly recognised as functional disorders by experts in their respective fields.

Qualitative research has the potential to highlight marginalised experiences, restore agency and connection, and guide care and research which addresses what is most important to individuals affected by a condition (Todres et al., 2009).

Systematic reviews synthesising qualitative research can inform practice, identify unmet needs and future research agendas (Barnett-Page & Thomas, 2009; Seers, 2015).

To date the experiences of those with motor and/or sensory FND subtypes have not been explored systematically.

Aim

This review aimed to synthesise qualitative research exploring the experiences of people living with motor and/or sensory FND including those with Persistent Postural Perceptual Dizziness and functional drop attacks. Identifying their needs should inform service development, education for healthcare professionals and generate future research questions.

Method

The review was pre-registered on PROSPERO (Bailey et al., 2021). Five databases were systematically searched (Medline, PsychInfo, Web of Science, Embase and Cinahl) in November 2022, updated in June 2023 as well as forward and back citation searching and consulting relevant experts. Data from included papers was extracted by two authors and studies were critically appraised using the Critical Appraisal Skills Programme (CASP). Data was thematically analysed and synthesised using both text-based and illustrative collaborations with co-authors with lived experience of FND.

Results

From 4868 unique records screened 12 papers were included in the synthesis describing the views of 156 people with FND. The analytic themes represented an interaction between body and mind, in relation with self, healthcare professionals and wider society. The overarching theme was **uncertainty**; about what caused FND and how to live with it. Uncertainty was underpinned by four analytic themes;

1. Navigating challenging healthcare interactions: a long journey from dismissal to diagnosis
2. Loss of power and control (and how to regain it)
3. Who or what is responsible?
4. Living with a visible disability and an invisible illness

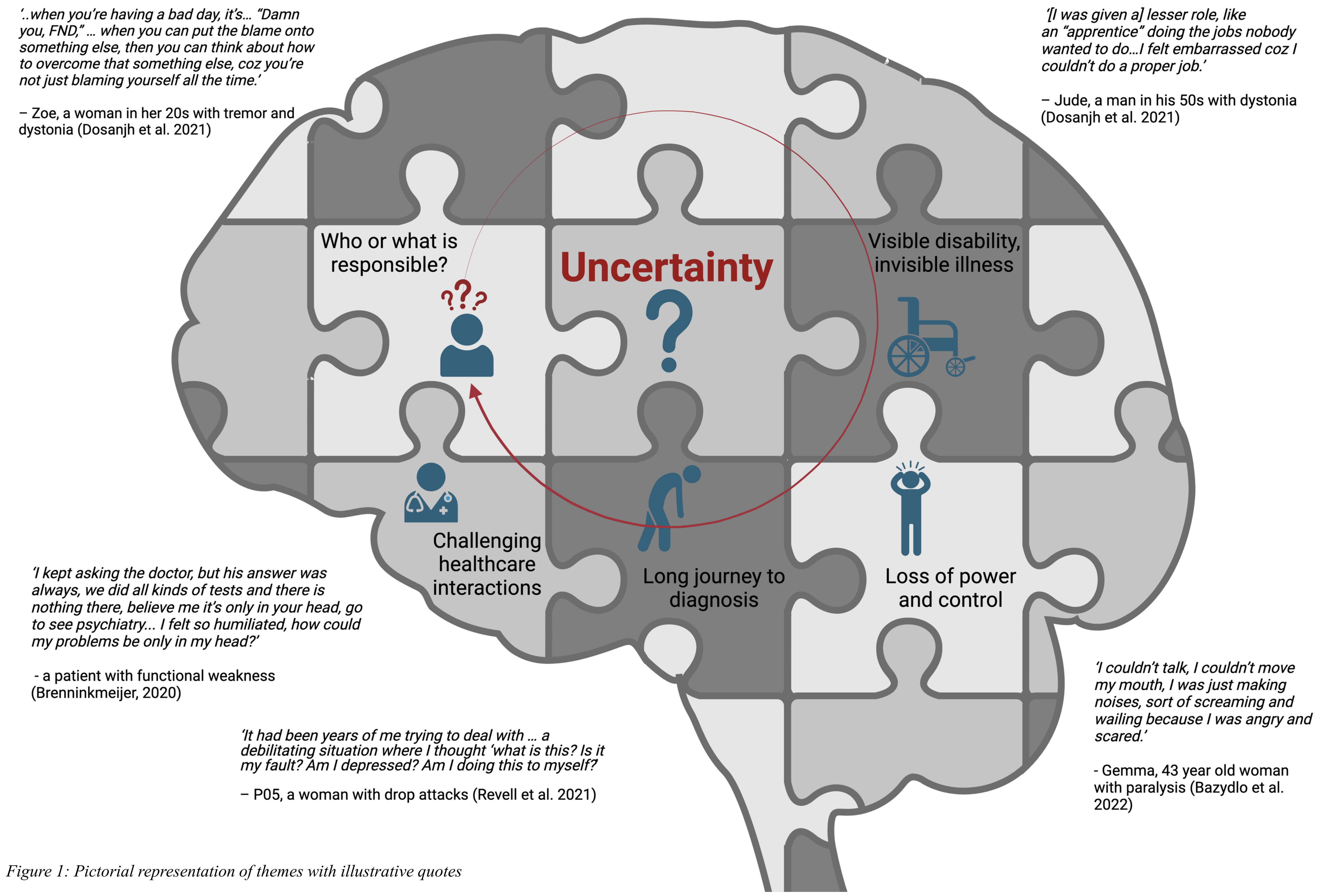

Figure 1: Pictorial representation of themes with illustrative quotes

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Conclusions

People with motor and/or sensory functional disorders experience significant disability, stigma, self-blame and functional impairment. Early and clear diagnosis, validation and practical support for living with FND should form part of multidisciplinary care. Co-produced service development, research agendas and education for clinicians, patients and the public could reduce stigma and improve the experiences of people with FND.

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