An agenda for functional neurological disorders: care and research

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This special suite of articles outline the challenges faced by patients, families, clinicians, and researchers with Functional Neurological Disorders (FND) and proposes a draft research agenda for the field to meet and hopefully systematically overcome those challenges.

The inspiration for these articles comes from a multi-year conference series investigating syndromes at the mind-body interface that do not cleanly fit into the traditional diagnostic and treatment silos employed by medicine, science, and society. We believe that FND are a paradigmatic example of such confounding and disabling disorders and remind us the importance of a fresh perspective that is engendered by discussions with multiple diverse stakeholders.

The evolution of our thinking began with a conference in 2016 which led to a paper that attempted to address the relationship between disorders that create diagnostic and treatment uncertainty for the clinician and patient and the intimate entanglement between stigma and uncertainty. Like others in the field, this paper also proposed that FND was a better and less stigmatizing term for defining this group of disorders than the older and more pejorative terminology of "Psychogenic Disorders" (Rommelfanger, et al, 2017). However, we also noted that changing the name alone will not suffice, as the hidden negative assumptions of stigma are tenacious and require a deeper understanding and systemic change.

The four papers in this volume of *CNS Spectrums* are the culmination of two additional international conferences and a writing group meeting that occured in March of 2020 that attempt to promote necessary systemic change in the clinical encounter with FND. The unifying theme of this writing group was to produce a series of papers that summarize the current state of knowledge while proposing a draft research agenda for the future. These papers focus on innovative and more expansive ways for exploring stigma, the assessment and diagnosis of FND, treatment interventions, and pathophysiology of FND.

One paper in this series (MacDuffie et al, 2020) reminds us that we have much farther to go and much to learn from other fields in reducing stigma around FND both for healthcare providers and for patients who may harbor self-directed stigma for their condition. In this paper we recognize that stigma does not only impact lived experience, diagnosis, and treatment, but also FND as a research topic worthy of funding in its own right. MacDuffie and colleagues outline a research strategy that explores the prevalence and context of stigma; a systematic assessment of the ways in which stigma impact the clinical care trajectory and establishment of best practices for addressing stigma in FND in the clinical encounter.

Intimately related to stigma is the process of diagnosis and treatment. Research directions for both of these aspects of FND are at varying stages of maturity, acceptability, and adoption. At times, this process has seemed so frustratingly overcomplicated that healthcare providers have turned to using different terms for diagnosis in charts and also move toward successful plans that are either long term, multi-disciplinary, or sometimes simply best guesses. Some issues are inherent to the diverse healthcare systems and contexts where patients interface with healthcare providers. On a fundamental level, the authors of the second paper in this series advocate for more research that aims to "see the whole picture" (Lidstone et al, 2020). Lidstone and colleagues call for a "3-step diagnostic triad" and put forward opportunities to bridge gaps such as 1) identifying non-motor diagnostic criteria 2) accumulating deeper understanding of the neuropsychiatric phenotypes and 3) and designing treatment protocols tailored to the constellations of symptoms manifesting in the syndrome and varying etiologies of FND. The third article by LaFaver et al, (LaFaver et al, 2020) complements the Lidstone et al article. It summarizes treatment strategies that are currently available to patients suffering from this heterogeneous syndrome. These range from the "Stepped Care" treatment approach promulgated by Jon Stone and colleagues in the UK to current work with evidence-based psychotherapies to physiatry-based interventions. The research agenda discusses the challenges posed by the the heterogeneity of the syndrome and highlights opportunities to address challenges in clinical trial design and dissemination of results.

As diseases are often hoped to be legitimized by biologizing them, many have pointed toward a prioritization of identifying biological underpinnings of FND. While this research is

critical, in this special issue, we identify how a wider scope of research from biological to psychological and even sociological could greatly benefit patients and families with FND, one that is not overly reductionist, yet also invites new exciting venues of research (Rommelfanger et al, 2017). These themes are present in the LaFaver article, but also can be seen as the heart of the last article in the issue. The fourth paper by Perez and colleagues focus on what is known about the biology of FND which is primarily focused on imaging and neuropsychiatry (Perez et al, 2020). The research agenda focuses on pathophysiology and encourages a brain circuit-oriented approach that can bridge symptoms and manifestations to "aberrant constructs" such as perceived agency, emotion processing, attention, and interoception.

We are grateful for the continued sustained energy of patients, advocates, healthcare providers, and researchers in this field and are hopeful for deeper transformation and progress in this under-served community. We offer this special issue as a framework for existing researchers in the field as well as outline a research agenda to garner fruitful engagement with government-sponsored funding agencies as well as foundations who are ready to boldly address disorders that will pay dividends not only for FND, but also for fields that have faced medical uncertainty and pushed traditional clinical boundaries.

References

1. Rommelfanger KS, Factor SA, LaRoche S, Rosen P, Young R, Rapaport MH. Disentangling stigma from functional neurological disorders: conference report and roadmap for the future. *Front Neurol*. 2017;**8**:106.
2. MacDuffie KE, Grubbs L, Best T, et al. Stigma and FND: a research agenda targeting the clinical encounter. *CNS Spectr*. 2020.
3. Lidstone SC, Nassif W, Juncos J, Factor SA, Lang AE. Diagnosing functional neurological disorder: seeing the whole picture. *CNS Spectr*. 2020.
4. LaFaver K, LaFrance WC, Price ME, Rosen PB, Rapaport MH. Treatment of functional neurological disorder: current state, future directions, and a research agenda. *CNS Spectr*. 2020.
5. Drane DL, Fani N, Hallett M, Khalsa SS, Perez DL, Roberts NAA. Framework for understanding the pathophysiology of functional neurological disorder. *CNS Spectr*. 2020.