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The Artfulness of FND: Redefining a stigmatized condition

Jennifer (Jen) Sebring, PhD Candidate
College of Community & Global Health
University of Manitoba

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Presenter: Jen Sebring

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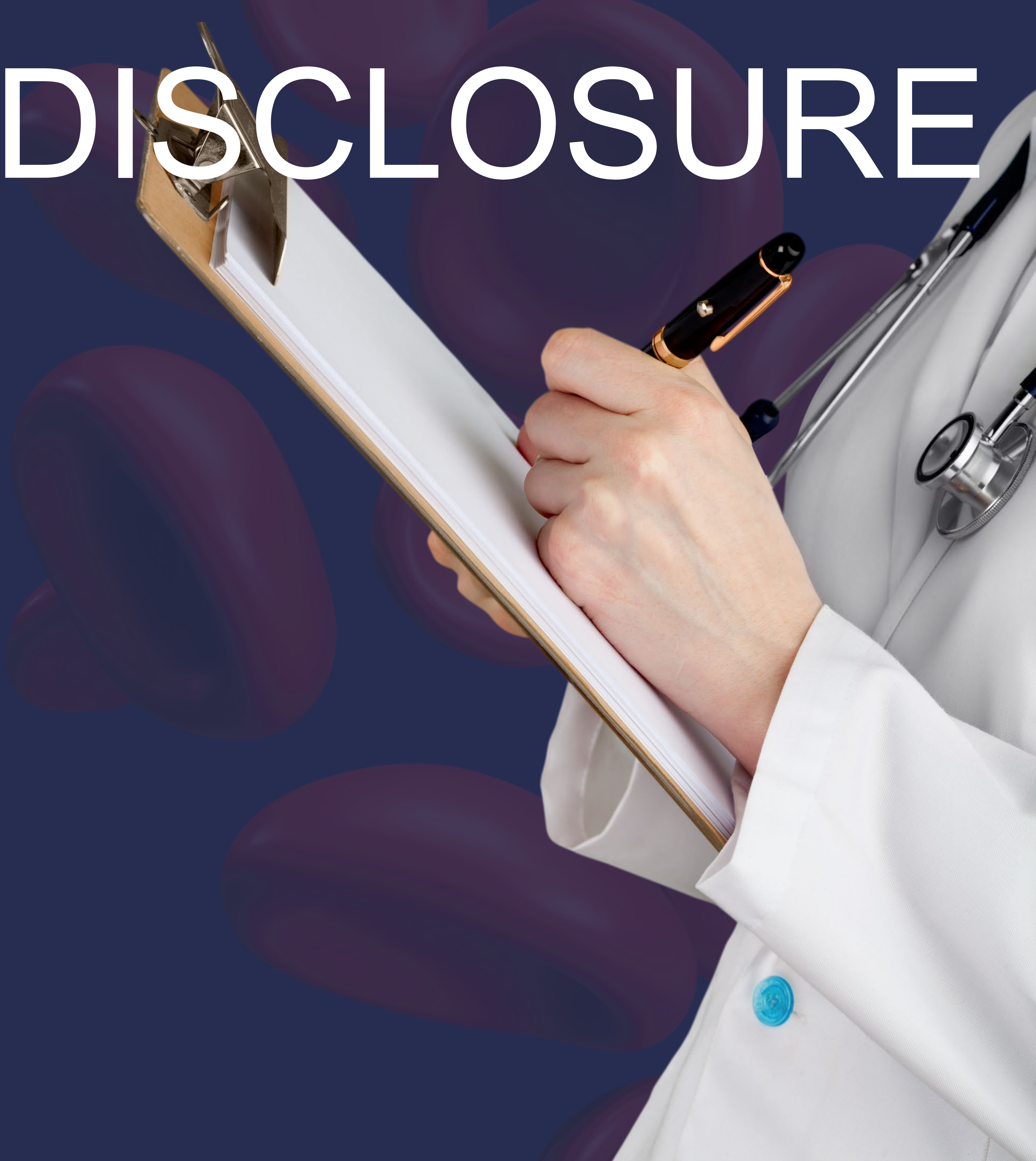

DISCLOSURE OF FINANC

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INTRODUCTION

- Functional neurological disorder (FND) is an umbrella term for a variety of neurological symptoms that have no “organic” cause – understood to be an issue of brain function rather than brain structure
- Ongoing “paradigm shift” from previous diagnosis of conversion disorder to improve understanding of this condition and address the considerable stigma that currently hinders patient care

STUDY OBJECTIVES

This study had two objectives:

1) to understand how people living with FND navigate and cope with their illness amid medical uncertainty, stigma, and a lack of services and supports, and;

2) promote renewed understandings of FND in clinical contexts to improve patient care

METHODOLOGY

- Patient-oriented qualitative research project in partnership with FND Together, a patient-led advocacy organization
- Narrative inquiry (Riessman 2007), semi-structured interviews with 23 adults living with FND in Canada
- Arts-based workshop process with subset of interviewees including an additional concluding interview
- Analysis & case selection: Thematic narrative analysis using critical social theory, selected an “information rich” case that captured some of the themes from the broader group
- Study approved by the University of Manitoba Health Research Ethics Board

FINDINGS

- Participants developed and relied on their creativity, resourcefulness, and self-advocacy to piece together a network of supports and redefine what it meant to live with FND - embodying Douglas et. al's (2020) concept of living 'artfully' with illness. Their success in this endeavour was contingent on having a supportive, knowledgeable primary care physician and considerable social, interpersonal and economic resources.

FINDINGS: Example Narrative

- Greg – older, white man (65-74 age bracket) living in rural British Columbia
  - Presented to family doctor with numbness and tingling in arms and legs, struggling with movement (“really having to fight for movement”) and eventually tremors and muscle weakness
  - Family doctor was quick to refer him to neurology, after seeing a couple neurologists he was diagnosed and referred to a FND specialist. Due to the COVID-19 pandemic, he was able to access virtual neuroeducation relatively quickly.

FINDINGS: Greg’s Story

- Greg began to learn more about the function of the brain, especially as it relates to movement and the mind-body connection, and became fascinated. It prompted him to rethink his life through these lenses:
- *I'm very much a ‘think-y’ kind of guy…I don't really pay much attention to what's going on in my body. My preset was that you know the body was just there to kind of move my enormous brain from place to place so it could do its thing*.
- He related this dissociation, a common FND symptom and mechanism, back to his childhood history of migraines, and then depression in earlier adulthood, both modes of being that were a “kind of retreat from life” as opposed to “physically moving into” whatever was going on around him.

FINDINGS: Greg’s Story

- *I've since sort of found like there's lots of things that are not happening [in my body] that I'm not really sensing. So there's more a practice of the sensory side of things. You know, even like feeling the actual movement.*
- He turned to art – photography – as a way of practicing the “sensory side of things” and redefining his relationship to movement:
- *The neurologist who diagnosed FND told me what differentiated FND from Parkinson’s was that FND tremors were distractible. If I was directed to do a task with the right hand, the tremors in my left diminished or stopped, a [positive diagnostic] sign for FND. This prompted me to purchase [a camera] along with a tripod as I couldn’t steady the camera in my hands…*

FINDINGS: Greg’s Story

- *The tremors and spasms would fade away while I focused on composing an image in the viewfinder, so I practiced this kind of moving – stillness – as a type of therapy. Over many, many months ordered motion was restored for longer periods of time.*
- He was selective in the type of camera he used – one that had tactile elements and more manual controls than automatic, to encourage the kind of sensory engagement he was looking for.
- Greg also employed the help of a massage therapist with a background in dance, who took a holistic view of the body and its functions to rework his relationship to movement. He now considers himself not cured, but “more integrated” of body and mind and is happy with his recovery progress.

IMPLICATIONS FOR CLINICAL

- WHAT MIGHT CARE LOOK LIKE WHEN WE CENTER THE CREATIVITY, CURIOSITY, AND RESOURCEFULNESS OF PEOPLE WITH FND?
    - Greg embodied the above characteristics AND had access to up-to-date information about FND, allied health services, supportive family and friends, as well as a helpful primary care provider and financial resources to facilitate treatment
    - Importance of meaning-making: making sense of the symptoms within the specific context of one's life history
    - Expanding what treatment looks like or means while paying attention to accessibility of services

CLINICAL CONSULT STRATE

- Acknowledge that FND is an emerging area of study but share what is known
- Highlight that the experience, management of, and recovery from FND can be different for everyone, and part of treatment is figuring out what that means for them and what is helpful
- Commit to follow-up/ongoing support
- Attend to social dimensions of health: what other supports and outlets do they have? What resources do they have access to? What might complicate access to these resources?
- Referrals – consider allied health professionals, and if cost is an issue, are there community-based practitioners or programs available to alleviate financial barriers?

CONCLUSION

- Primary care physicians play an important role in helping patients co-create a path forward to live well with FND. By harnessing the creativity and resourcefulness demonstrated by people living with such complex health conditions, physicians and patients may be able to successfully navigate FND despite a lack of systemic support.

THANK YOU!

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