Bridging the Divide: Functional Neurological Disorder In Neurology and Psychiatry

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  - American Academy of Neurology
  - Children's Clinical Research Advisory Committee
  - Brain and Behavior Research Foundation
- My funded research has no relationship with today's topic
- I want to Deputize you in improving the lives of children with FND





Why do Neurologists Treat FND Differently?

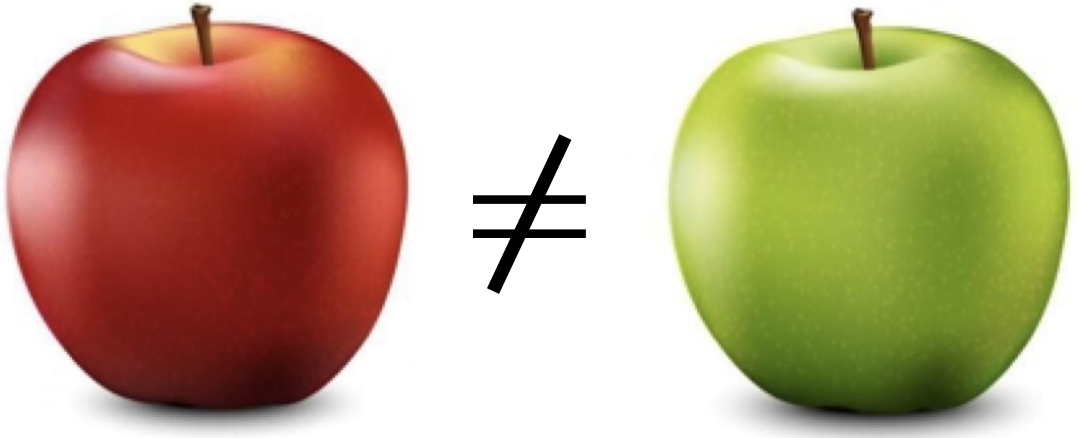
- Fear of conflict
- Ingrained schmuckery
- Fatalism
- Lack of confidence

} - Willful mediocrity; weaponized incompetence

- Feared lack of resources (time, reimbursement, support)

Why do N chiatry?

- Out of date knowled
- They don't know wh
- Because they're allo



How Common is FND?

- Prevalence in adults: 50 per 100,000
- Prevalence in pediatrics (Historic): 1.3 to 6.0 per 100,000
- Comparison: NMDA Receptor Encephalitis: 0.15 per 100,000
- Challenges to an accurate count: transient nature of symptoms, scattered care provision, lack of expertise in recognizing FND in children, severity bias in referrals/diagnosis
- Better approach: structured, longitudinal screening in a contained population
- Yong et al., Dev Med Child Neurol (2023)
- 3-10x higher prevalence: 18.3 per 100,000

- Lived experience: almost every day encounter with FND



Yong et al., Dev Med Child Neurol (2023)

How Does FND Present?

- Most common presentation:
  - mixed seizure/motor/sensory (Yong, 2023; de Gusmao, 2014; Raper et al., 2019)
  - also reported: seizures > all other types
  - Take home message: over time, >1 phenotype is the norm
- 78% have predisposing factors
  #1: self-reported psychiatric symptoms
  #2: pressure from academic/sporting achievement
- 37% had precipitating factors, most commonly infection/inflammation and physical trauma/injury. - Yong et al., 2023
  - Abuse is uncommon in kids (0-3%), but keep your eyes open.
- How a functional disorder presents depends on local "preference":
  Paralysis in Singapore
  Non-epileptic seizures in Türkiyé
  Fainting attacks in India

How Accurate are FND Diagnoses?

- An FND diagnosis is accurate 96-99% of the time – similar to the accuracy for Alzheimer, epilepsy, and higher than for many neurological diagnoses
  - Largest such study: 1144 consecutive new Neurology patients; misdiagnosis in 0.3%
    - J Stone, *Brain*, 2009



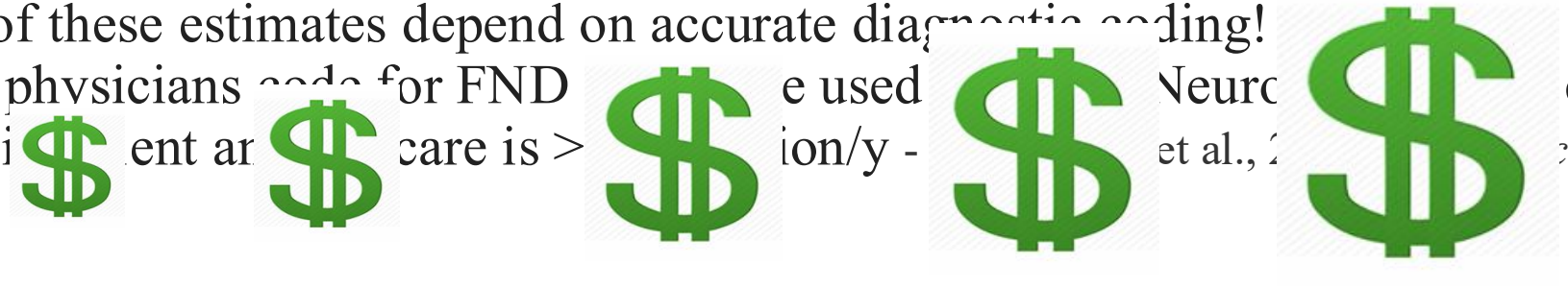
- How much expertise does one n
  - Our prospective collection of ic ER:
    If Neurology residents inclu x,
    Attending Neurologists con of the time
    And the FND diagnosis wa ases
    - de Gusmao et al., 2014

- "Hysteria is sometimes said to i is is a highly misleading statement. The mimicry can on of the signs of hysteria or content with perfunctory exami
  , 1922

FND is Costly

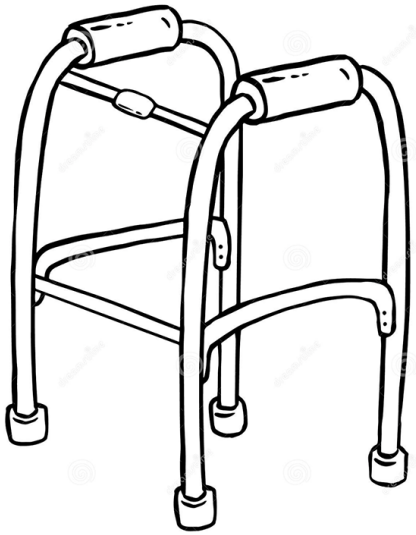
- Estimated lifetime cost of treating Functional Seizures: $450,727 - Szaflarski et al., 2003
- Stephen CD et al., *JAMA Neurology*, 2021
  - Compared with other neurological disorders, FND:
    - more frequently resulted in inpatient admissions
    - had higher rates of inpatient testing
    - inpatient costs were about the same: $1.1 billion for adults, comparable to ALS; $75 million for kids, comparable to all demyelinating diseases combined

- But all of these estimates depend on accurate diagnostic coding!
  - If all physicians code for FND e used Neuro cost for i ent ar care is > ion/y - et al., 2 *ctrums*



FND is Disabling

- For motor FND (abnormal movement or weakness):
  - 23.8% were wheelchair dependent - Valladão Theuer et al., 2020
  - Mean percentage of patients same/worse at follow-up: 39% - Gelauff et al., 2014
- Similar for functional seizures (FS)
  - Dropping out of school, workforce is common - Doss and Plioplys, 2018
  - Relative to those with epilepsy, patients with FS have:
    - lower Health-Related QOL
    - worse moo
    - lifetime co FS = to intractabl l., 2003
- Pediatric FND pa ER (de Gusmao et al
  - were sympton uration of 7.4 wee
  - missed a mear chool
  - and parents m 3 days of work





FND is Disabling

Comparing organic and functional diagnoses:

- number of missed days of school…
- number of missed parental work days…
- self reported level of physical independence…

FND patients are just as disabled as their organic disorder counterparts – and more disabled if you factor in stigma.

Key Message

- "I can tell that you're really suffering with this. The good news is that we have a clear diagnosis, so we can move directly to finding the best treatment for you."

FND Localizes to Specific Brain Networks

Neurologists are obsessed with picking the one spot that explains symptoms.

Brain imaging in FND is "normal" in FND – but this is true in many Neuro/Psych disorders

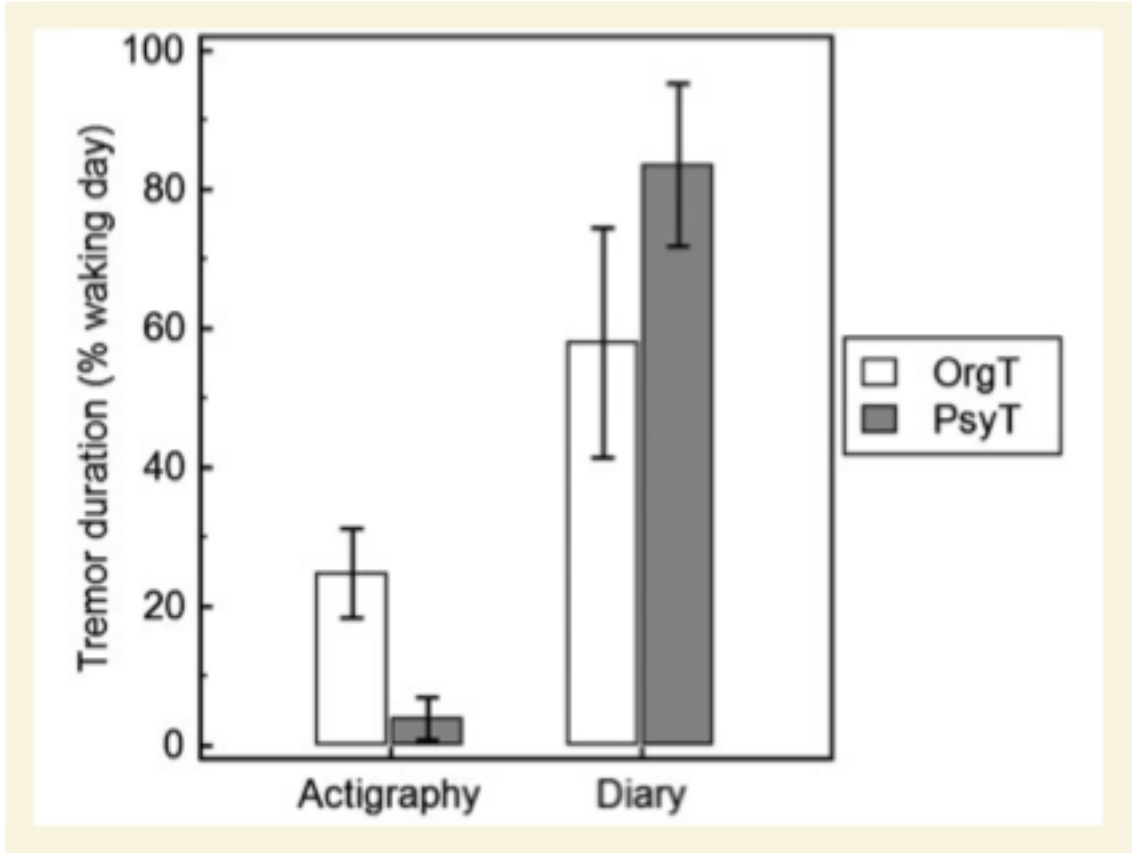
Patients with FND have abnormal perception of timing and volitional control

- Abnormal sense of intention preceding voluntary movements in functional tremor.
  - Edwards MJ et al., Neuropsychologia 2011
- Action-effect binding is decreased in functional movement disorder
  - Kranick SM et al, Movement Disorders 2013

Patients with FND over-estimate their disability, as measured objectively:

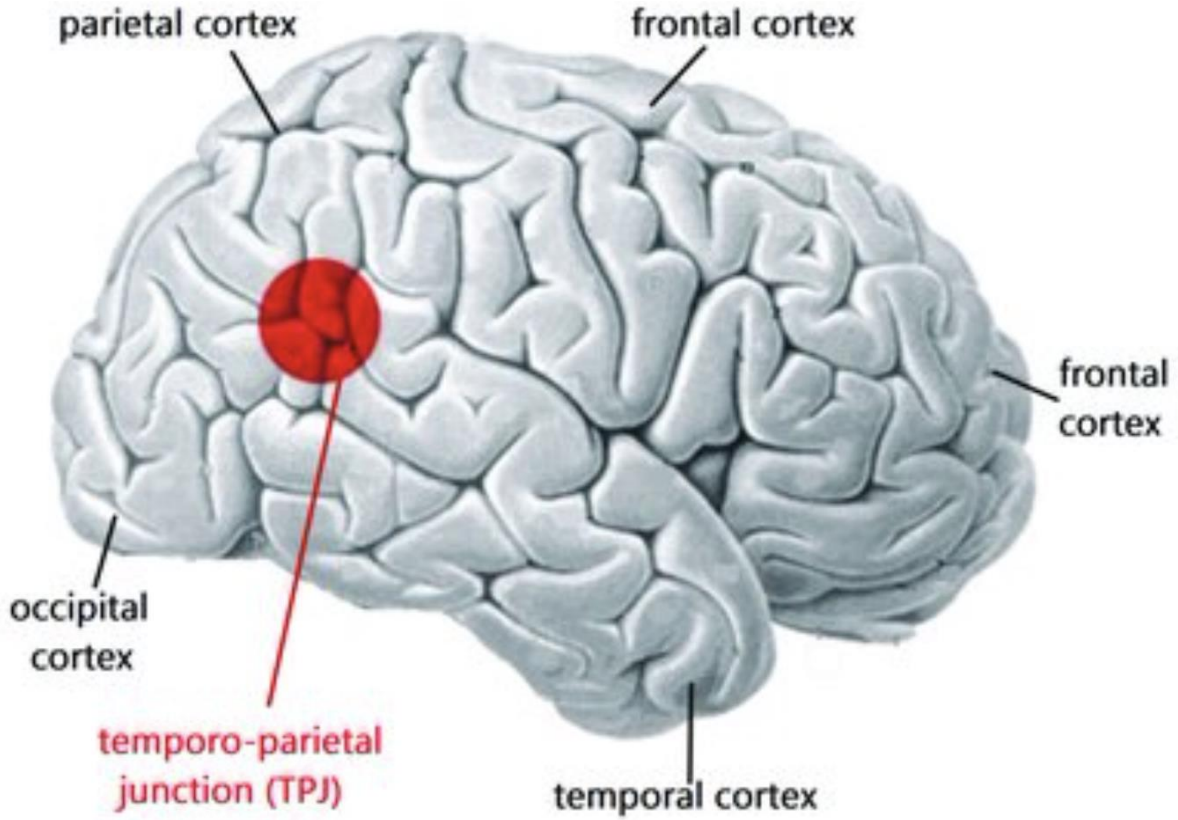
Believing is perceiving: mismatch between self-report and actigraphy in psychogenic tremor. – I Paree´s et al., *Brain* 2011

Subjects with tremor (Organic vs. Psychogenic) wore actigraphy monitors and simultaneously logged the % of time impacted by tremor



Impaired self-agency in functional movement disorders: A resting-state fMRI study - CW Maurer et al., *Neurology* 2016

- In patients with functional movement disorders, the R. temporoparietal junction (rTPJ) has decreased functional connectivity with sensory and motor areas
- rTPJ serves movement to actual sensory fee
- rTPJ inacti – when the self-generated n ness



Impaired sense of agency in functional movement disorders: An fMRI study – FB Nahab et al., *PLOS One*, 2017

- Used a virtual reality environment that subject could control – but level of control varied
- Patients with FND failed to activate the rTPJ in response to loss of motor control
- Parallel rating scales: functional patients overestimated control when they had little control, and underestimated control when they had complete control



Many Modalities Reveal Brain Abnormalities in FND

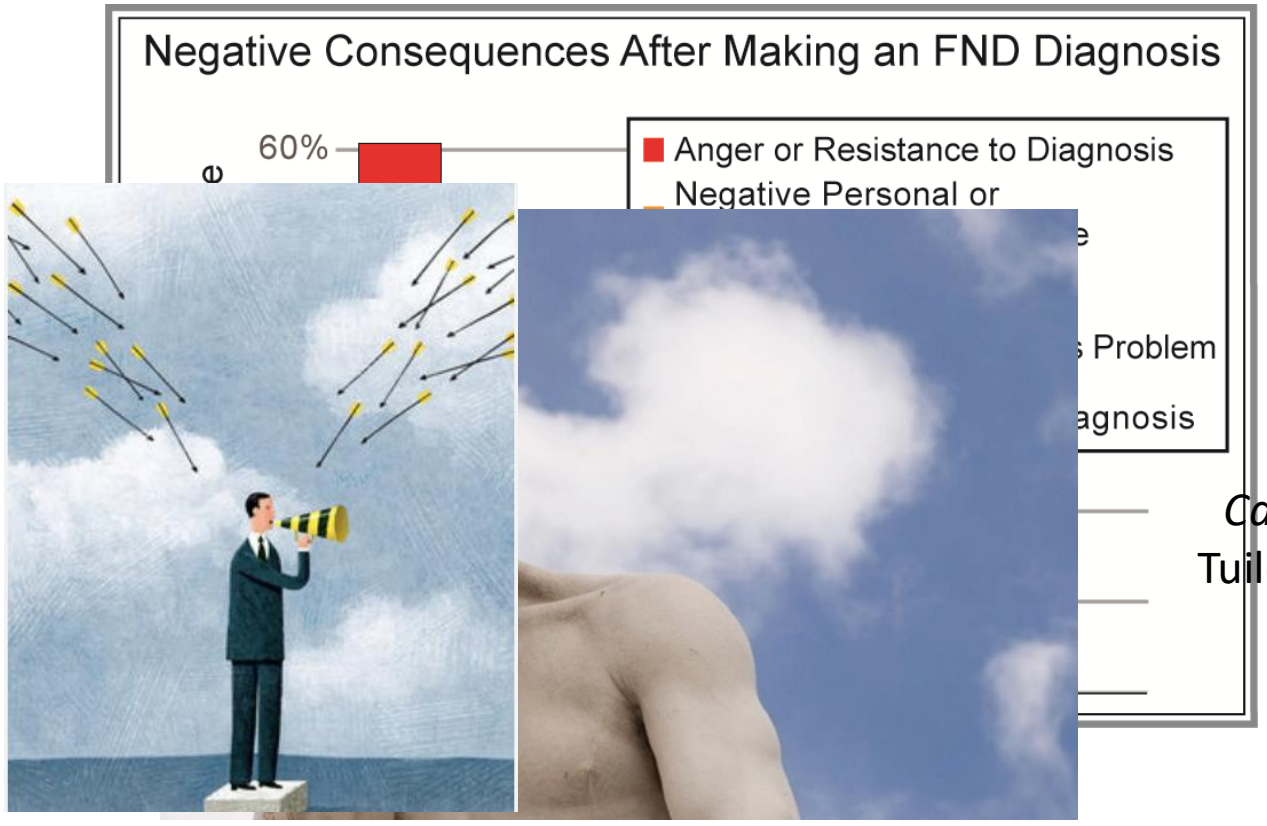
- At least 8 peer reviewed publications used PET or SPECT to investigate functional disorders
- Other MRI methods – volumetry, shape analysis, tractography – have also found region-specific abnormalities in functional patients
- Anyone who tells you "There's nothing wrong in FND" hasn't kept up with the research

Key message:

- "This is a brain-based problem, and we need to use brain-based solutions. The good news is that we know how to re-train your brain to not create this problem."

Why Do Physicians Fear FND?

- Physicians speak differently when they speak about FND – but why?
- Physicians may carry their own trauma regarding FND - Herbert LD et al., 2021
  Free text prompt: How have negative experiences with FND altered your practice?
  - 190 respondents (46%) described their experiences



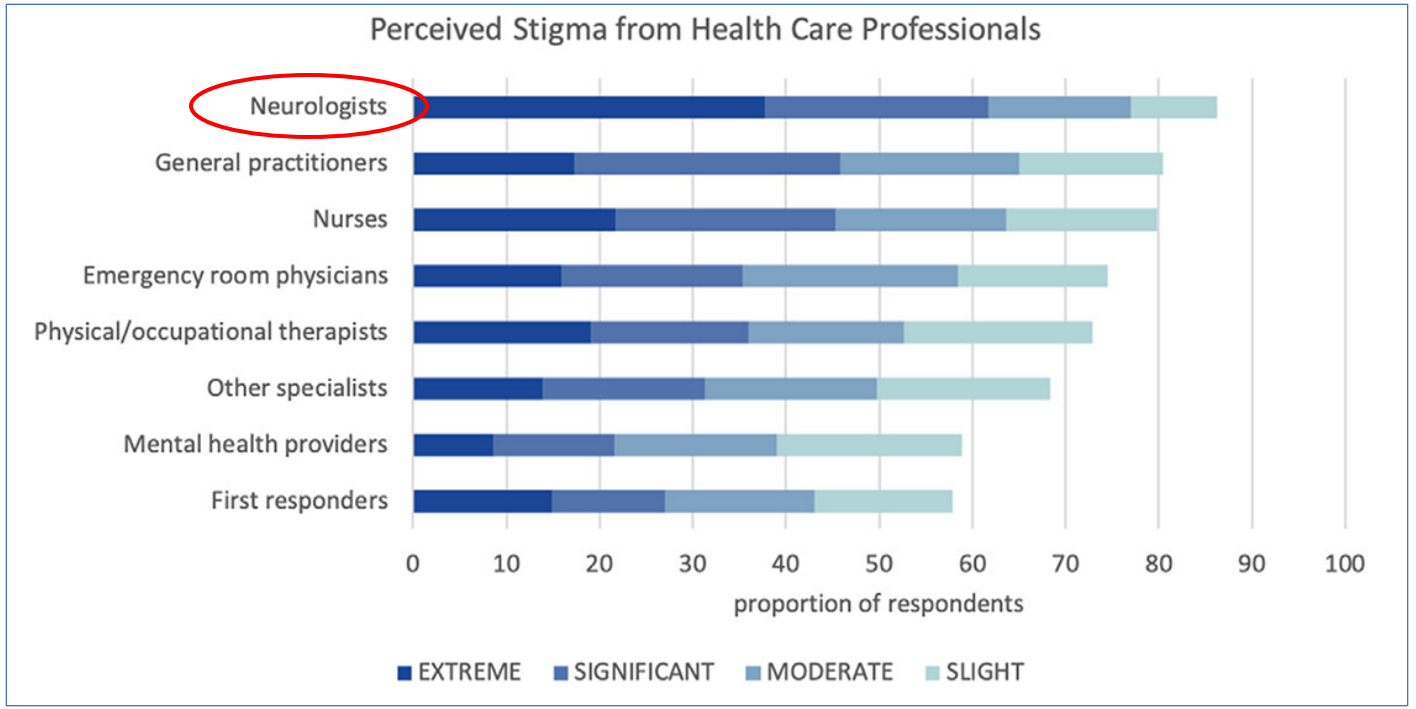
Caïn by Henri Vidal,
Tuileries Garden, Paris

FND and the Hidden Curriculum

- For which diseases did your Senior Resident:
  - Pantomime the physical exam for comic effect?
  - Refuse a consult because, “We don’t deal with this $_ _τ”?
  - Distinguish your patient’s symptoms from “real” disease?
- Recall a time when your Attending:
  - Told your patient they were faking and should leave?
  - Told you that caring was pointless?
  - Blamed your patient for filling a bed when sick people had to wait?
- Priorities reflect values:
  - Did your medical school curriculum include FND?
  - Do local medical societies include FND updates in CME?

FND is a Stigmatized Disorder

- Physicians speak differently when they speak about FND
  - Medical culture excuses treating these patients poorly.
    My experience: mocking of, and disdain for FND patients is common



MacDuffie et al.,
CNS Spectrums, 2020

FND is a Stigmatized Disorder

- Physicians speak differently when they speak about FND - Monzoni et al., 2011
  - Measured Formulation Effort (FE): a ubiquitous feature of verbal communication, manifested by silences, repetitions, syllable stretching, self-interruptions, etc.



Patient Perspectives



“Changing the culture of care for children and adolescents with functional neurological disorder” - Kozlowska et al., 2021

Do Our Biases Affect Treatment of FND?

- Large study of CMS claims data. Admission vs. Discharge home from the ER?
  - Women sent home 16% more than men
  - Poor sent home 11% more than rich
  - Young sent home 370% more than old

  Who is most likely to develop FND? The harmed and the vulnerable



- "Functional neurological disorder is a feminist issue" - McLoughlin C et al.
  - "people with FND continue to suffer subtle and overt forms of discrimination by clinicians, researchers and the public."



Fatalism in FND: a Failure to Try?

- Children do far better than adults
- Raper et al. (Arch Dis Child, 2019) – 77% resolved by adulthood (median f/u: 8.3 years)
- Pal et al. (J Child Neurol, 2022) – 84% improved or resolved by 3 mo; 100% resolution if the child had no more than 2 functional symptoms and no other somatic symptoms
- Regardless of the exact % that improve, kids clearly do better than adults. All the more motivation to help them get better faster!
- Adult outcomes:
  - 32% showed reliable improvement
- Predictors of improvement:
  - Therapist specialization
  - Closer integration between neurological and psychotherapeutic care

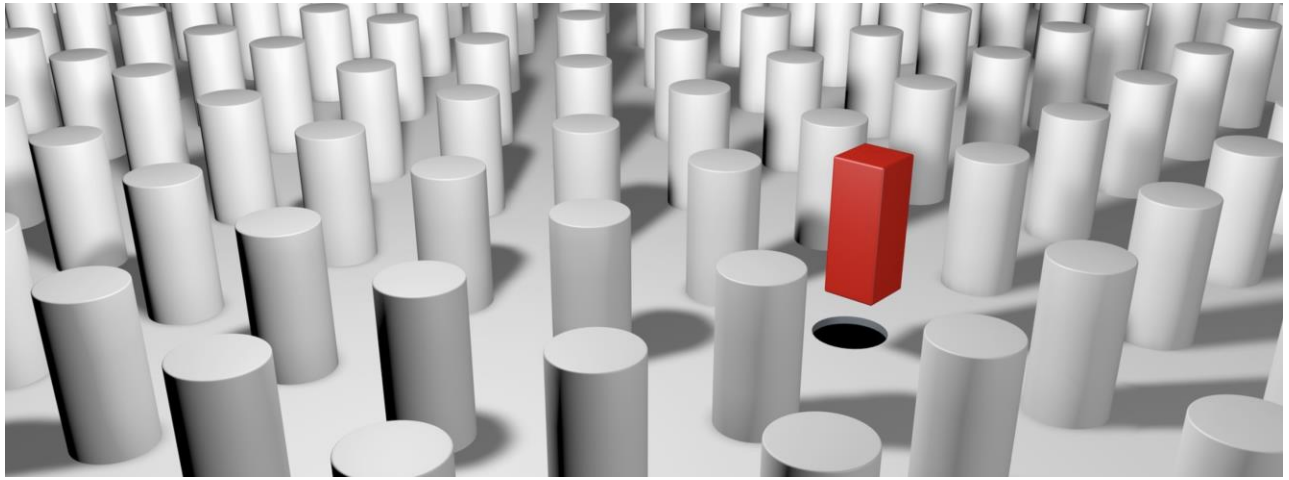


Michaelis et al. 2026

- How many cases of adult FND were actually continuations of childhood FND? Could we prevent (some) adult FND by improving our care for kids with FND?

FND is Treatable

- 3 treatment modalities with published efficacy - Vassilopoulos et al, 2022
  ReACT (Retraining and Control Therapy – A. Fobian and colleagues, UAB)
  FND-specific CBT
  FND-specific rehabilitation



Communication is Key

- "Explanation as treatment for functional neurologic disorders"

  - J Stone, A Carson, M Hallett, *Handbook Clin Neurol.* 2016;139:543-553.

- "Enhancing the communication of functional neurological disorder diagnosis: a multidisciplinary education session"

  - Cope et al., Eur J Neurol. 2020 Sep 12.

- Enhancing the quality of FND communication faces a deeper problem: when physicians don't communicate at all.





Why Don't Neurologists Communicate an FND Dx?

- Think about a few of your common diagnoses, things you recognize intuitively
- For those disorders, how often do you hide the diagnosis from the patient?
- How can we quantify private and privileged communication?



- Review of all inpatient neurology consults x 3y, selecting for dx of FND
- In parallel: Survey of child neurologists nationwide, 460 respondents
- When Neurologists write "This is FND" in their note, how often do they communicate it?
- Non-epileptic seizures with EEG confirmation – the "gold standard" for FND diagnosis.
  Predicted: 96.2% would communicate

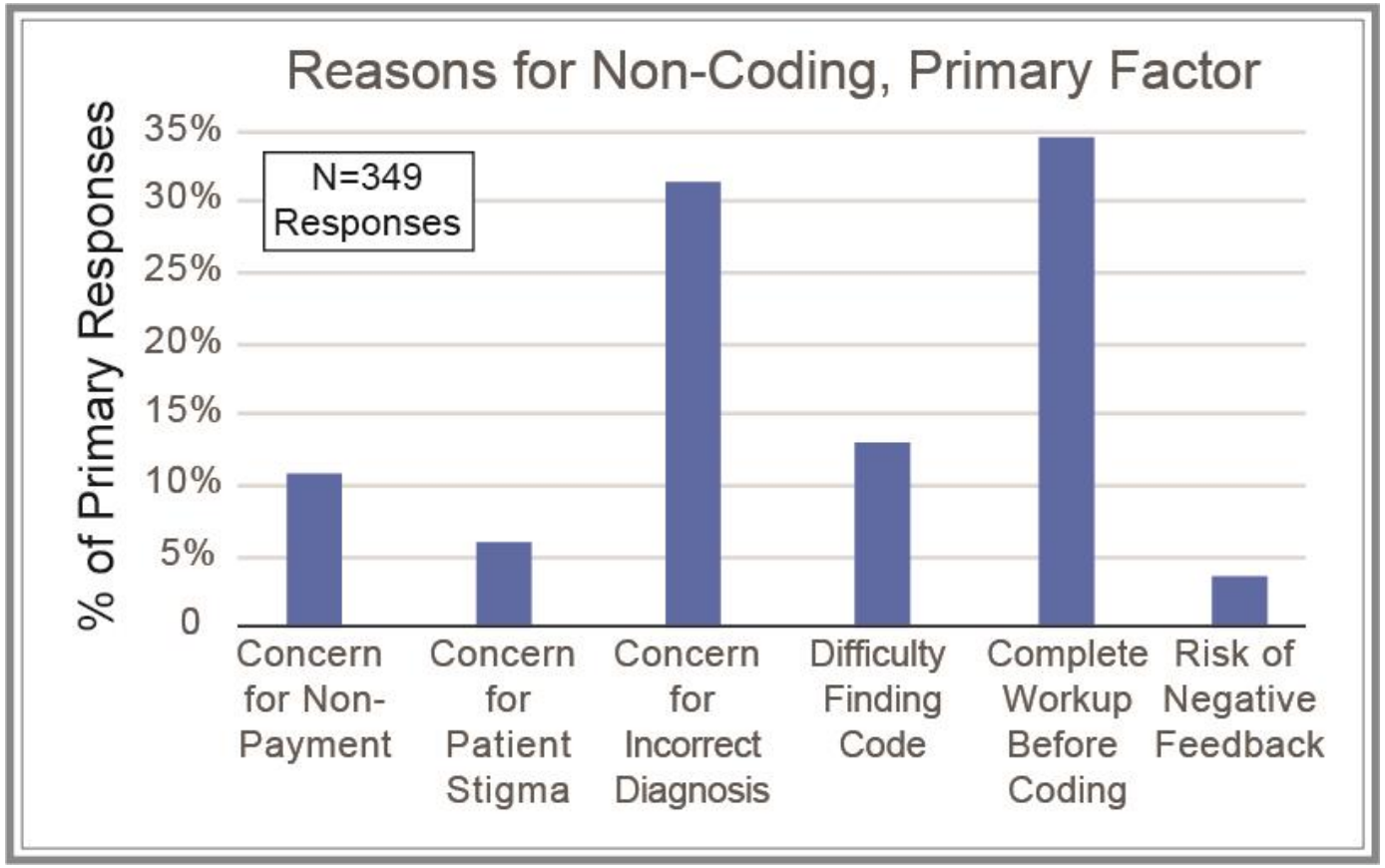
- Estimates of FND prevalence and cost are likely <u>5-fold higher</u> than we think

Why Don't Neurologists Code for FND? We considered the following factors:

1. Business of medicine knowledge: FND codes, fear of non-payment
2. Concern that coding for FND will produce harm/stigma to the patient
3. Concern that coding for FND will produce harm for the physician
4. General practice of coding for symptoms (rather than underlying disorders) until confirmatory testing is complete
5. Concern about the accuracy of the diagnosis
6. Bias against the category of FND, independent of diagnostic certainty

Why don’t neurologists code for FND?

“If you have previously diagnosed or had high suspicion for FND, but you did not use the ICD-10 codes for FND or a specific manifestation of FND, what are the reasons you did not include these codes?”



Herbert LD et al., 2021

Diagnostic Thresholds in FND vs. Organic Disorders

- Every diagnostic scenario must reach a threshold of plausibility before clinicians move from a potential to a pragmatic, actionable diagnosis.
- Do Neurologists use differing thresholds of completion for FND vs. other neuro disorders?

6 Common Clinical Scenarios

"Q1. Please think back to the last patient you saw whose history and neurologic examination were consistent with seizure disorder, and apply the following scenario to that encounter."

	Suspected Diagnosis, with Type of Data Provided					
Data:	Epileptic Seizure	Guillain-Barre Syndrome	Pseudotumor Cerebri	Non-Epileptic Seizure, no EEG	Astasia Abasia	Non-Epileptic Seizure, + EEG
Supportive Physical Exam Findings	–	+	+	–	+	–
Specific Finding on Diagnostic Study	–	–	+	–	–	+



Diagnostic Thresholds in FND vs. Other Disorders

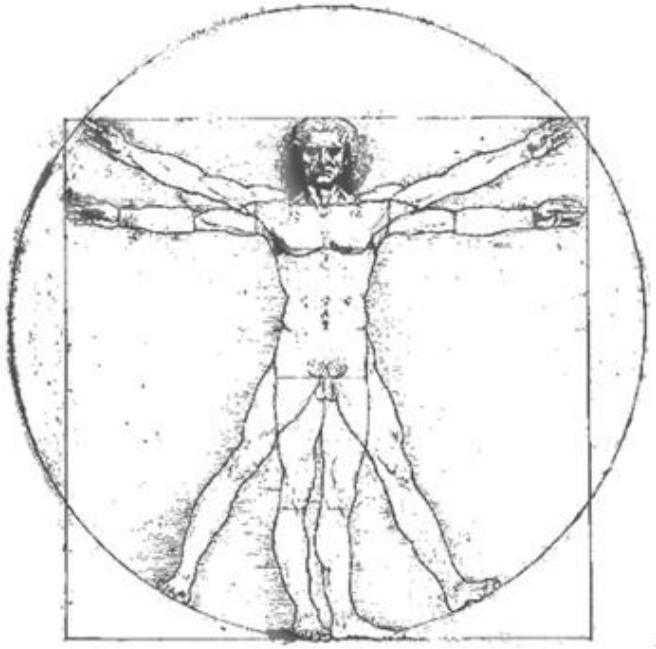
- Every diagnostic scenario must reach a threshold of plausibility before clinicians move from a potential to a pragmatic, actionable diagnosis.
- Do Neurologists use differing thresholds of completion for FND vs. other neuro disorders?
- MDs used more stringent thresholds for diagnosing FND.
  When the workup was explicitly incomplete:
  - For organic disorders, 81.0% were willing to code
  - For non-epileptic seizure, only 57.3% were willing to code ($t=9.68$, $p<4.0\times10^{-20}$)
- Physicians v wo consistent.
  These MD ss t both organic and
  functional gro ce in FND.
- The sole fac gh FND?
  The belief th usi





Trust in the Physical Exam

- 31% described "concern for making an incorrect diagnosis" as the 1º or 2º factor leading them to not utilize FND-related codes.
- Guillain-Barre and astasia-abasia scenarios presented equal amounts of data.
- Respondents coded astasia-abasia > than for Guillain-Barre (by 16.5%)
- When cohort divided by con n shifted:
  - those who trusted their ex F=7.1, $p<8.2x10^{-3}$)
  - those who rated "concern higher (NS)
- Concern that FND was a mis nder-valuing the physical examination by 4.2-fold.



Concern for Non-payment for FND Care

- 9.7% would not code due to fear of non-payment *
- 11.5% reported difficulty finding appropriate diagnostic codes
- Only associated factor: duration of clinical practice
  - physicians who completed training 10-25 years (OR: 3.8; $p<5.3x10^{-3}$)
  - or >25 years (OR: 3.3; $p<0.015$, NS) prior

  Older MDs were 3x more likely to identify these educational deficits as their 1º reason for not coding for FND.

Knowledge Gap: Business of Medicine

- Addressing the myth of non-payment of FND-related ICD10 codes:
  Reviewed all instances of F44.X
  - billed during the 3 years covered in our chart review
  - for all of Pediatrics (Neurology plus all other Divisions)
  - for both inpatient and outpatient encounters
- 141 encounters utilized F44 codes:
  - 94% were paid outright
  - Of the 6% that were not paid, all were for administrative errors
- Summary: there is no policy of non-payment for FND codes
- Demonstrated previously: Mark et al., Psychiatr Serv. (2018)

Bias Against FND as a Category

- Two scenarios had equal information (history, exam, testing): epileptic vs. functional seizure
- When Neurologists coded for functional seizures, what factors correlated with that decision?

Five factors were significant predictors of non-coding for Functional Seizure:

Factor	Odds Ratio
Fear of misdiagnosis	0.10
Complete workup	0.13
Fear of stigma	0.06
Diagnosis of Exclusion	0.41
Inability to find codes	0.23

View of FND as a Diagnosis of Exclusion

52% of our respondents viewed FND as a diagnosis of exclusion (DoE)

- Factors positively correlated with the view that FND is a DoE
  - preference to complete diagnostic workup before coding (OR=3.3, $p<2.1x10^{-5}$)
  - working in private practice (OR 2.0, $p<7.6x10^{-3}$).
- Other demographic & personal factors had no significant correlation
- Our local colleagues – who only coded for FND 22% of the time – were significantly less-likely to believe that FND is a DoE
  - In practices where this incorrect belief is stronger, coding is likely even less

Why Don’t Neurologists Trust their Exam?

- Resident-level suspicion for FND has a 94% PPV for an accurate, stable FND diagnosis
  - de Gusmao et al., 2014

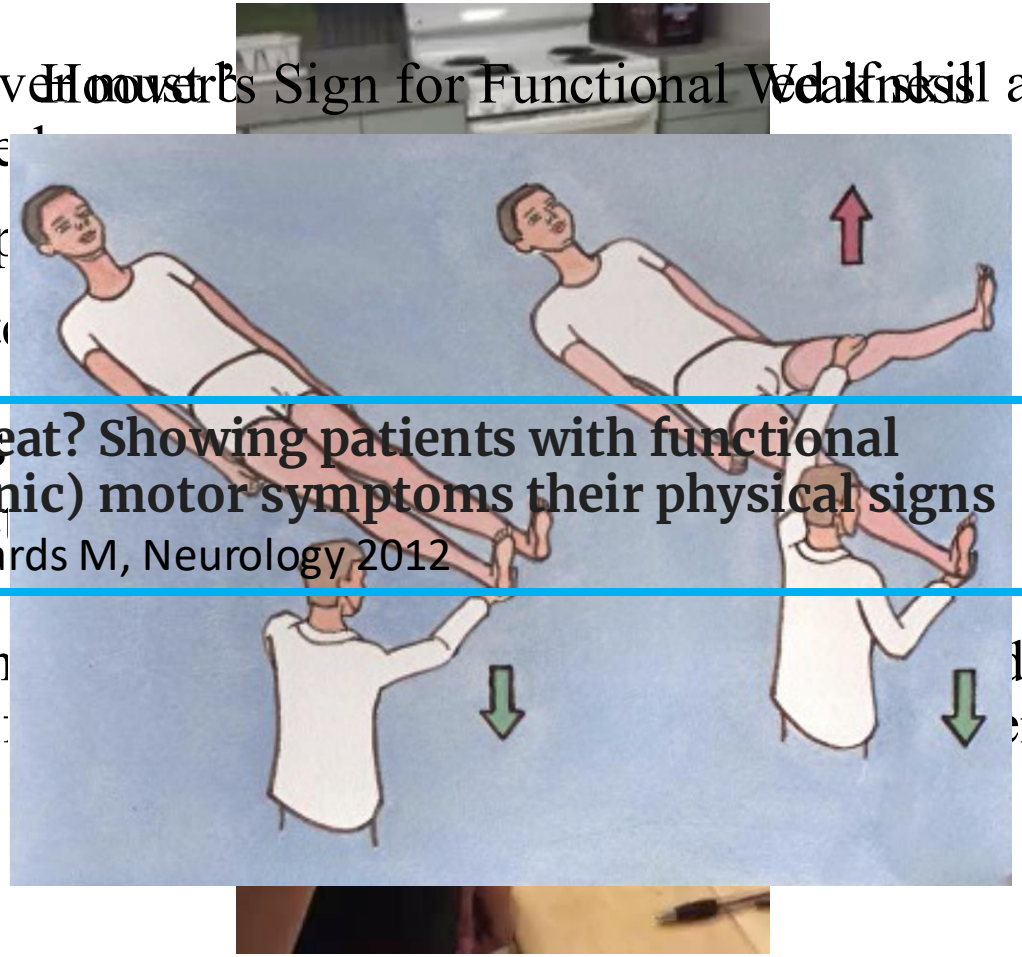
  So why don’t we deploy the most important tool in the Neurology bag?
- We haven’t learned the right exam
- We use our hammer without using common sense
- We’ve internalized The Big Lie: FND is not, and never has been, a diagnosis of exclusion

FND has Distinct, Testable Features

"Listen to your patient; he is telling you the diagnosis." - Sir William Osler

- Any physical exam maneuver [illegible] Hoover's Sign for Functional Weakness [illegible] and fluidity are to be achieve[illegible]
- Many papers available on p[illegible]
- These are not tricks for cat[illegible]

Tremor: Res[illegible]
with Distrac[illegible]



Trick or Treat? Showing patients with functional (psychogenic) motor symptoms their physical signs
Stone J, Edwards M, Neurology 2012

- "Like a lot of diseases, Fun[illegible] doctors know on sight. It's easy to recognize the speci[illegible]nts."

When is the Right Time to do Better?



"No, Thursday's out. How about never—is never good for you?"

Poor Prognosis in FND – How Much is on Us?

Would we allow our own behavior in other corners of our lives?

We have to eliminate:

- Bruising language
- Disdain for the suffering of children
- Willful mediocrity and weaponized incompetence

Eliminating stigma requires culture change

How to Help Physicians do Better with FND:

- Physicians may need to work through their own traumatic FND experiences
- Difficult tasks require specific training and accountability
- Unlearning falsehoods:
  - Rate of misdiagnosis in FND is 0.4 - 4%, the same as other neurological disorder
  - FND is not a diagnosis of exclusion
  - Anyone can bill for FND care
- Acknowledging that we are required to work towards better
  - These children have been harmed, often by us
  - We are not our best selves with FND patients
  - We have allowed ourselves to be bad at this

FND Support Pack

How schools can support Functional Neurological Disorder (FND) recovery



School & Family Conversations

The purpose of this packet is to help your student and school nurse know how to regulate the nervous system and return to class.

Some questions you can ask:

- Can you schedule a parent/school meeting to discuss the FND Response Plan?
- Can an individualized learning plan help your student have scheduled daily coping time?
- What are the school nurse and counselor's recommendations to help the student stay in school and cope with physical sensations and overwhelming thoughts?



What is FND?

FND is a problem with the functioning of the nervous system. It is the brain's inability to send and receive signals properly. FND is the second most common diagnosis in Neurology clinics after headache. The Pandemic and lock down have dramatically increased rates of FND in children and adults. Promoting normalcy and healthy coping skills in the classroom is important for your students, especially those with FND.

> We recommend in person school for students with functional neurological disorder. Progress and recovery happen when we face challenges with the support of our community.
>
> -FND Society



Share resources with your school

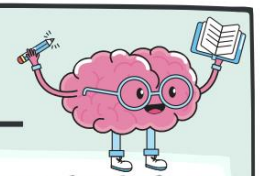
Pediatric FND Consortium

FND HOPE

- FND Response Plan
- Classroom friendly calming tips
- Web Resources: www.fndhope.org
- Provider Name/Number:
-

_____

FND RESPONSE PLAN



NAME/DOB: _____

I, _____, HAVE BEEN DIAGNOSED WITH FUNCTIONAL NEUROLOGICAL DISORDER, BY MY HEALTH CARE PROVIDER. SYMPTOMS CAN HAPPEN THROUGHOUT THE DAY OR IN EPISODES. EPISODES ARE SIMILAR TO PANIC ATTACKS, **ARE NOT MEDICAL EMERGENCIES** AND GET BETTER WHEN RESPONDED TO CORRECTLY.

FOR ME, FND LOOKS LIKE:

MY WARNING SIGNS

WHAT TO DO DURING

R
SE.

THE TOOLS TO GET THROUGH IT. I AM HERE WHEN YOU ARE READY." THEN GIVE ME PRIVACY AND SPACE.

WHAT TO DO IF AN EPISODE IS ABOUT TO HAPPEN

- ☐ GIVE ME A REASSURING NONVERBAL SIGNAL THAT I KNOW MEANS, "I'M HERE. YOU ARE GOING TO BE OKAY."
- ☐ REMIND ME TO USE A COPING SKILL TO REGULATE MY NERVOUS SYSTEM.
- ☐ _____

WHAT TO DO AFTER

REINVOLVE ME/RETURN ME TO CLASS.

PRAISE ME ONE-ON-ONE FOR COPING THROUGH MY SYMPTOMS.

PLEASE WAIT UNTIL THE END OF THE DAY TO CONTACT MY GUARDIAN USING THEIR PREFERRED METHOD.

WHAT NOT TO DO

- ☐ DO NOT CALL AN AMBULANCE UNLESS INJURED. (PLEASE CHECK BASED ON INDIVIDUAL NEED.)
- DO NOT REMOVE ME FROM SCHOOL.
- DO NOT BEHAVE FRANTICALLY.
- DO NOT TIME THE EPISODES. UNLIKE EPILEPSY, THE CARE DOES NOT CHANGE AFTER 5 MINUTES.

Pediatric FND Consortium

FND HOPE

Provider Signature: _____ Date: _____

Provider Name: _____ Provider Contact: _____

Take-home Pearls

- FND diagnosis is based on Positive Exam Findings – not just the absence of "true" symptoms.
- Your patient may have both functional *and* organic disease. This is not uncommon.
- Building trust in the diagnosis is difficult without trust in the exam. Share your findings as a way of building trust with the patient/family.
- Acknowledge that past medical experiences may have been bruising, and proactively unburden.
- Acknowledge that the lives of patient and family have been seriously disrupted. Take their disability seriously.

tl; dr

- Treat FND like any other disorder
- Start and end with kindness

Thank you!

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A Diatribe on “Diagnoses of Exclusion”

Presenting functional disorders as “diagnoses of exclusion” is actively harmful

1) It communicates to families that we find these diagnoses dubious and disconcerting;

2) It requires one to “exclude” diagnoses which are not clinically supported, wasting resources and exposing patients to overtesting and delay in treatment;

3) Most damaging, it implicitly encourages clinicians to mistrust their physical exam and clinical history, the two most important features in making a neurologic diagnosis.

FND is not, and never has been, a diagnosis of exclusion



