1 PANDAS & PANS An Integrative Approach

Dr. Jill Crista

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3 Course details

- 7 Modules on-demand
- Downloadable slides and resources mentioned are found in each Module under the Materials tab

- Quizzes are at the end of the lessons where they pertain
- Certificates of completion are sent for all student types
- CME/CE certificates please allow 1 week
- Access for 1 year
- Survey
- 30-day money back guarantee, as long as not more than 25% of course materials have been downloaded or videos viewed.
- Copyrighted course assets and equal exchange ~
 Please support my work and the voluminous hours I've spent collating my years of experience and research to put together this scientific presentation.

Please resist your healer's heart urge to share widely - even and especially if you're a parent! I understand - I've been there.

And I paid my kids' doctors with gratitude.

I ask for the same consideration.

4 Overview

- Course Outline
- 1. Symptoms
- 2. Mechanisms
- 3. Diagnostics
- 4. Conventional treatment approach
- 5. Integrative treatment approach

- 6. Recovery essentials
- 7. Cases

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Paradigm Shift

6 Overview

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7 Autoimmune encephalopathies

- PANDAS = pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection
- PANS = pediatric acute-onset neuropsychiatric syndrome
- A third category? "PLANS" or "NADAL"
- Autoimmune encephalitis (AE) found to be as common as infectious encephalitis (Mayo Clinic 2018)

- Antecedent state: immune depletion
- Autoimmune trigger: INFECTIONS &/or TOXICANTS
- Target tissues depend on specific type of AE
- PANDAS/PANS/BGE ~ brain stem/basal ganglia, GI, kidneys (theorized)

8 Overview

- Incidence: Lacking large population data, however roughly estimated as 1 in 200-250 children
- Prevalence: males>females 2.6:1
- FHx: autoimmune disease
- Autoimmune relapsing-remitting pattern
- Average 3 month pattern
- Challenge of mgmt:

Wax: flare/natural progression or new exposure?

Wane: treatment effect or natural remission?

- Some variation PANDAS vs PANS
- Different diagnostic criteria

9 Symptoms in order of prevalence

- Separation anxiety
- Inability to concentrate
- Urinary frequency, urgency, or urinary accidents

- Handwriting deterioration
- Alterations in sleep insomnia, night terrors, inability to sleep alone
- Behavioral regression
- Hyper-alert appearance; enlarged pupils
- Hyperactivity
- Inattentiveness
- Tics
- Learning difficulties
- Short-term memory loss
- Aggression
- Sensory alterations hypersensitive or insensitive
- Disordered eating
- Hallucinations, rarely

10 Clinically Observed Symptoms: PANS/PANDAS

- Separation anxiety (98%)
- Inability to concentrate (90%)
- Urinary frequency, urgency, or urinary accidents (90%)
- Handwriting deterioration (90%)
- Alterations in sleep insomnia, night terrors, inability to sleep alone (80%)

- Behavioral regression
- Hyper-alert appearance; enlarged pupils (80%)
- Hyperactivity, inattentiveness (70%)
- Tics (70%)
- Learning difficulties (60%)
- Short-term memory loss (60%)
- Aggression (60%)
- Sensory alterations hypersensitive or insensitive (40%)
- History of repeat UTIs or sinusitis
- Disordered eating (20%)
- Hallucinations (10%)
- Clinical observations O'Hara/Wells presentation WNDA Annual Conference 2021

11 PANS Phenotype (n=43)

- Anxiety 43 (100)
- Panic/Somatica 15 (35)
- Generalized anxiety disorder (GAD) 20 (47)
- Separation anxiety disorder (SAD) 33 (77)
- Social phobia 12 (28)
- School avoidancea 20 (47)

- Mood and behavioral symptoms 43 (100)
- Emotional lability and/or increased irritability 43 (100)
- Anxious/Depressed 19 (46)
- Withdrawal/Depression 10 (24)
- Somatic complaints 9 (22)
- Social problems 2 (5)
- Thought problems 21 (51)
- Attention problems 8 (20)
- Rule-breaking behavior 3 (7)
- Aggressive behavior 12 (29)
- Suicidality (n=33) 10 (30)
- Behavioral regression 36 (84)
- Deterioration in school performance 36 (88)
- Sleep disturbance 36 (84)
- Tics 30 (70)
- Simple 30 (70)
- Complex 12 (28)
- Sensory abnormalities 26 (61)
- Urinary problems 24 (56)

- Frequent urination (pollakiuria) 19 (44)
- Enuresis 11 (26)
- Handwriting deterioration; 7–14 years (n=30) 17 (57)
- Food restriction 20 (47)
- ADHD diagnosis 20 (47)
- Inattention 11 (26)
- Impulsivity/hyperactivity 14 (33)
- Oppositionality 11 (26)
- Irrational thinking and/or psychotic symptoms 12 (28)
- Visual hallucinations 5 (12)
- Olfactory hallucinations 4 (9)
- Auditory hallucinations 3 (7)
- Mydriasis 10 (23)
- Choreiform movements 9 (21)
- Anorexia (not caused by PANS-OCD) 5 (12)
- Visuospatial/Motor impairment (n=42) 28 (67)
- Obsessive compulsive symptoms
- Harm to self and/or others 39 (91)
- Ordering and/or arranging, symmetry 30 (70)

- Contamination 29 (67)
- Sexual and/or religious 16 (37)
- Collecting and/or hoarding 14 (32)

12 Stanford PANS Clinic Cohort (n=220)

- Anxiety (97%)
- Sensory amplification (97%)
- Sleep issues (93%)
 - Insomnia, nightmares, restless sleep, reverse cycling, REM motor disinhibition = REM Behavior Disorder (RBD)
- Obsessions & compulsions (92%) [major criteria]
- Mood disorder (92%)
- Irritability/aggression (90%)
- Behavioral regression (73%)
- Deterioration in school (72%)
- Urinary symptoms (66%)
- Eating restriction (53%) [major criteria]

• Frankovich, Stanford PANS clinic, presentation Neuroimmune conference May23

13 Symptoms in order of prevalence

Separation anxiety

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14 PANDAS Dx Criteria

Category 1 ~Presence of OCD (compulsions) and/or tics, particularly multiple, complex or unusual tics
[must be severe enough to meet criteria for OCD or a tic disorder and interfere with the patient's ability to function
at pre-illness levels]

- Category 2 ~Age Requirement
 [first evidence between 3yo and puberty]
- Category 3 ~Acute onset and/or episodic (relapsing-remitting) course
 [with abrupt, dramatic, debilitating exacerbations of existing symptoms, at which time the symptoms seem to
 "explode" in severity]
- Category 4 ~ Association with Group A Streptococcal (GAS) infection [evidence of GAS infection found without apparent pharyngitis]
- Category 5 ~ Association with Neurological Abnormalities
 [abnormal results on neurological examination. Motoric hyperactivity and adventitious movements such as choreiform movements or tics are particularly common]
- Comorbidities ~ anorexia, urinary frequency, mydriasis, insomnia, abd pain boys>girls
- PMID: 28989283

15 PANS Dx Criteria

- Category 1 ~ An abrupt, acute, dramatic onset of obsessive-compulsive disorder or eating restriction [many treating docs see a nuanced acute onset, owing to congenitally acquired infxns]
- Category 2 ~ 2 co-morbid symptoms (also sudden onset):
 - 1. Anxiety (commonly severe separation anxiety)
 - 2. Sensory dysregulation (light, sound, and/or pain) or motor abnormalities (handwriting deterioration, piano fingers, tics, or motoric hyperactivity)
 - 3. Behavioral (developmental) regression
 - 4. Deterioration in cognitive functioning (school performance)
 - 5. Mood disorder (emotional lability, depression, irritability, rage)
 - 6. Urinary symptoms (polyuria, urge, enuresis)
 - 7. Severe sleep disturbances

[most have 5-6 co-morbid symptoms]

- Category 3 ~ Symptoms not better explained by a known neurologic or medical disorder
- Category 4 ~ Age requirement any, as long as pediatric
- Comorbidities ~ mydriasis, generalized abdominal pain
- PMID: 28989283

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17 Differential Diagnoses

- Obsessive-compulsive disorder (non-PANDAS/PANS)
- Tourette syndrome
- Sydenham's chorea (acute rheumatic fever)
- Abuse and/or trauma
- Other encephalidities (AE, NMDA-R)
- Medications, recreational drugs
- Post-concussive autoimmune hypophysitis
- Tumor
- Cerebral vasculitis, autoimmune vasculitis, Behcet's syndrome (Herpes?)
- And of course, myriad unrecognized contributing environmental and infectious factors (ie: novel viruses)

18 PANDAS or SC?

- Is PANDAS actually Sydenham's chorea 2.0?
- Both are the result of a Strep infection.
- Both conditions have OCD sxs and involuntary or unpredictable movements as part of their dx criteria.
- May have ID'd what distinguishes them different Strep proteins may lead more to one than the other, but it remains a diagnostic challenge.
- About 1/3 with PANDAS or OCD have the choreiform movements seen in SC.
- SC may cause more severe OCD symptoms, while also resolving sooner than PANDAS.
- Be mindful of this close look-alike. SC is a common sx of rheumatic fever
- and therefore may require treatment strategies for RF.
- PMID: 25301689

19 Distinguishing from other AEs

- Distinguish by symptomatology that's missing.
- IE: NMDA-R AE
 - -seizures
 - -myoclonus
 - -coma
 - -focal neurological signs

20 Genetic Predisposition?

 PANS: HLA alleles: HLA-B 38, 52, 55 My own observations:

Snps related to IgG: Fcy Receptors Snps related to NTs: COMT, MAOA

Snps related to detox:

Phase I: CYP1A2, CYP1B1, CYP3A4 (mold)

Phase II: GSTM1, MTHFR, SUOX Snps related to histamine: DAO

21 OCD in children

- Obsessive-compulsive uncoupling
- Obsessions = thoughts ~
 Often involves a silent experience of intrusive thoughts
 Intrusive thoughts interrupt normal cognition = looping/lack of focus
 Cause = neuroinflammation impeding normal brain chemistry/fxn
- Compulsions = behaviors ~
 Involves a sense of lack of control
 Take control of what they can
- *By listening to these with an investigative mind, they often point to the causal issue.
 - controlling adherence to routines/everyone else must as well adrenals
 - avoidance of certain people strep carriers
 - food avoidance digesting increases LPS, neurological dysphagia
 - must look left or bad things a need for craniosacral re-alignment
 - hand-washing fear of further infection/need for immunomodulation

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- Symptoms
- Next up:
- Mechanisms