PANDAS/PANS

DIAGNOSIS AND TREATMENT

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OBJECTIVES

1. Working knowledge of PANDAS/PANS
2. Awareness of predisposition factors
3. Awareness of common misdiagnoses
4. Differences in presentation of OCD and PANDAS/PANS
5. Common tests and interpretations for PANDAS
6. Treatments Recommendations
7. Impact on School setting and school nurse’s role
In the early 1990’s, investigators at the National Institute of Mental Health (Drs. Susan Swedo, Henrietta Leonard, and Judith Rapoport) were doing studies of childhood-onset OCD and observed that some of the children had an unusually abrupt onset of symptoms.

The **NIMH Investigators discovered that the OCD, tics, and other symptoms usually occurred in the aftermath of a strong stimulant to the immune system**, such as a viral infection or bacterial infection in some of the children they were studying.
**PANS:** Pediatric Acute-onset Neuropsychiatric Syndrome

Commonly expanded to

*Pediatric Autoimmune Neuropsychiatric Syndrome.*
PANDAS:
Pediatric Autoimmune Neuropsychiatric Disorder Associated with *Streptococcal Infections*

**PANDAS** is a subset of PANS
SYMPTOMS

**OCD:** including but not limited to obsessive thoughts and rituals

**Tics:** involuntary movement/vocalization, usually sudden onset

**Separation anxiety:** not wanting to separate from caretaker

**Depression:** hopelessness, low self esteem, talk of suicide

**Generalized anxiety**

**Behavioral changes:** oppositional behaviors, irritability and rages

**Urinary frequency**

**Anorexia**

**Math and handwriting regression**

**Problems focusing:** mimics ADHD
PEDIATRIC OCD vs. PANDAS

PEDIATRIC OCD
- AGE OF ONSET: 8-12 YEARS
- TIMELINE: SUBCLINICAL SYMPTOMS BECOME MORE SEVERE OVER TIME
- CAUSES: LIKELY FAMILIAL/GENETIC LINK

PANDAS/PANS
- AGE OF ONSET: 4-14 YEARS OLD
- TIMELINE: ACUTE, DRAMATIC ONSET OF SYMPTOMS
- CAUSES: LIKELY AUTOIMMUNE ANTIBODIES MISTAKENLY ATTACKING THE BASAL GANGLIA
WHAT IS OCD?

UNWANTED AND REPEATED THOUGHTS, FEELINGS, IDEAS, SENSATIONS AND BEHAVIORS THAT DRIVE CHILDREN TO PERFORM REPEATED ACTIONS.

OFTEN THE CHILD CARRIES OUT THE BEHAVIOR TO STOP THE OBSESSIVE THOUGHTS
COMMON OCD THOUGHTS

FEAR OF CONTAMINATION
UNWANTED SEXUAL THOUGHTS
LOSING CONTROL: acting impulsive, blurting out
RELIGIOUS OBSESSIONS: concerns of offending God, end of the world
HARM: self harm or harming others

Source: International OCD Foundation
Common Compulsions

1. Washing and cleaning
2. Mental Compulsions - mental review, cancel a bad word with a good word, repetitive speech
3. Checking
4. Confessing or asking to get reassurance
A SURVEY OF PEDIATRIC ACUTE ONSET NEUROPSYCHIATRIC SYNDROME CHARACTERISTICS AND COURSE

698 PATIENTS WITH CLINICAL DIAGNOSIS OF PANS COMPLETED A 146 QUESTION SURVEY
SYMPTOMS

1. GENERALIZED ANXIETY - 96%
2. OCD 94%
3. MOOD LABILITY 90%
4. IRRITABILITY 89%
5. EXCESSIVE WORRY 87%
6. RAGES/MELTDOWNS 84%
7. SADNESS 83%
8. SENSORY DEFENSIVENESS 79%
9. HANDWRITING DETERIORATION 76%
10. DEFIANCE 75%
11. FATIGUE 75%
12. SPECIFIC PHOBIAS 74%
13. TICS-MOTOR 71%
14. BIZARRE THOUGHTS 69%
15. INSOMNIA 67%
16. HYPERACTIVITY - 66%
17. LOSS OF MATH SKILLS - 66%
18. STOMACH PAIN - 64%
19. CONFUSION - 64%
20. FREQUENT URINATION - 56%
21. LOSS OF APPETITE - 48%
22. TICS VOCAL - 57%
23. HALLUCINATION 36%
Mild Symptoms

- Clearly impaired in some settings, not all (home vs. school)
- OCD occupies 1-3 hours a day, does not create intractable obsessional fear.
- Able to attend school, with/without accommodations
- Separation anxiety and other symptoms manageable

Moderate Symptoms

- Anxiety and OCD occupy 50%-70% of thoughts and significantly interferes with activities
- School refusal but may be able to visit friends briefly
- Symptoms impair daily functioning but not incapacitating.
SEVERE SYMPTOMS

- Life threatening consequences result from severity of symptoms
  - Dangerous Impulsivity
  - Weight Loss (>10-15% of body mass)
- Extreme anxiety/fears occupy 80-90% of the day
- OCD too severe to attend school or leave the house
- Severe separation anxiety
- Other: irritability, emotional lability, extreme aggression
PREDISPOSING FACTORS

- Family history of autoimmune disease
- Immune deficiency
- MTHFR mutation
COMMON MISDIAGNOSES

- Bipolar Disorder
- ODD
- ADHD
- Schizophrenia
- Anorexia and other eating disorders
- Generalized anxiety disorder
- OCD
PANS/PANDAS IS A CLINICAL DIAGNOSIS

- Diagnosis based on signs, symptoms and medical history and NOT based on blood work or radiological testing
THREE PRONGED APPROACH TO TREATMENT

PANS is a broad spectrum of neuropsychiatric conditions with various etiologies. Thus treatment is based on three complementary modes of intervention:

- Treating the symptoms with psychoactive medications, psychotherapies (CBT and SSRIs)
- Removing the source of the inflammation with antimicrobial interventions. (antibiotics)
- Treating disturbances of the immune system with immunomodulatory and/or anti-inflammatory therapies. (NSAIDS, steroids, IVIG)

FIG 1: The PANS treatment triangle.
• 22.8% of the US Population is under 18 years old (73,673,073 children in the US)

• 1 in 5 children are known to have a mental health condition (14,734,615 in the US)

• Suicide is the 2nd leading cause of death for 15-24 year olds and the 3rd leading cause of death for 10-14 year olds in the US (June 2016)

• Many patients are misdiagnosed based on the symptoms being predominantly psychiatric in nature, but Post Infectious Encephalopathy (PANDAS/PANS) could account for more than 368,365 children.
PANS/PANDAS is not a rare disorder. Conservative estimates put the incidence of PANS/PANDAS at 1 in 200 children.

Diabetics under age 20 equal about 1 in 400 and 1 in 285 children can expect a diagnosis of cancer before age 20.

*Pans, Cans and Automobiles*, Jamie Candelaria Greene PhD, BCET
We are lacking multidisciplinary clinics across the US

Treatment Center Comparisons

1 in 400 youth under 20 have juvenile diabetes,
1 in 285 children under 20 will be diagnosed with a childhood cancer.
1 in 200 children nationwide conservatively have PANS/PANDAS (368,365)
Educators Role: Help identify students possibly affected by PANS/PANDAS

Symptoms commonly observed in the school setting:

- Regression of math skills
- Handwriting deterioration
- Increased ADHD symptoms
- Tics- Motor or Vocal
- ODD behavior
- OCD
- Frequent urination
- Rapid onset behavioral changes
Many of these children are in public schools. An IEP or 504 plan is in place to accommodate challenges to learning.

Some students are homebound on IEPs.

Many more are compelled to stay home, homeschooling or unschooling, due to school refusal.
School Nurse’s Role

1. Have a plan in place with the parent and child
   • let the child go home if no visible signs of sickness (example no fever since most PANS/ PANDAS kids don’t get fevers)
2. Notify parent of outbreaks of sickness if possible
3. Give Ibuprofen for headaches or symptoms if agreed upon by the treatment plan
4. Help educate the community and parents of school age children
PANS/PANDAS IMPACT ON SCHOOL

SYMPTOMS WAX AND WANE WITH FLARES:

1. LOSS OF ABILITY TO COMMUNICATE EFFECTIVELY (BOTH ORALLY AND IN WRITING)
2. UNABLE TO MAINTAIN FOCUS, ATTENTION AND EXECUTIVE FUNCTIONING
3. UNABLE TO BEHAVE IN AGE APPROPRIATE WAYS
4. UNABLE TO ADAPT TO TRANSITIONS OR STRESS
5. UNABLE MAINTAIN A PRIOR LEVEL OF STAMINA
6. SHORT TERM MEMORY LOSS
CLINICAL RESEARCH CONSORTIUM

Clinical Research Consortium
University of Arizona is one of the Founding Members of the National University Consortium on Pediatric Autoimmune Neurological Disorders
Questions?
Principles of treating neuroimmune disorders:

- Establish the correct diagnosis – diagnosis of exclusion (Chang et al, J Child Adol Psychopharm, 2015)
- Provide symptomatic relief – comprehensively treat symptoms causing the most distress (Thienemann et al, J Child Adol Psychopharm, 2017)
- Treat infections – therapeutic and prophylactic antibiotics (Cooperstock et al, J Child Adol Psychopharm, 2017)
- Treat neuroinflammation and post-infectious autoimmunity with anti-inflammatory and immunomodulatory interventions (Frankovich, J Child Adol Psychopharm, 2017)
- Evaluate effectiveness of treatment, modifying as warranted by relapsing and remitting symptoms (Swedo et al, J Child Adol Psychopharm, 2017)