PANS PANDAS

RESTRICTED EATING

Overview & Studies

Pediatric Acute-onset Neuropsychiatric Syndrome

Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections

ASPIRE
Alliance to Solve PANS &
Immune-Related Encephalopathies

Who Gets PANS/PANDAS?

- How Many Have PANS? Estimated at 1 in 200
- Below Age 8: 4.67 Boys: 1 Girl
- Above Age 8: 2.6 Boys: 1 Girl
- Average Age of Diagnosis: 3-13 years old
- Peak Age of Onset: 4-9yrs (69%)
- No Age Requirement: Symptoms can continue into adulthood & adult-onset can happen
- Family History: 70% of PANDAS families have a history of autoimmune or strep related illness

Key PANS PANDAS Points

- PANS/PANDAS is a medical condition
- PANS/PANDAS are clinical diagnoses
- Prompt diagnosis & treatment=better outcomes
- PANS triggers are not just strep
- They are essentially spectrum disorders
- The three prongs of the treatment guidelines must be individualized per patient & per flare
- Symptoms are relapsing and remitting
- Please don't blame patients for their illness

Restricted Eating and OCD are the two major symptoms in the diagnostic criteria for PANS. Roughly 50% of PANS patients will have some degree of restrictive eating, and about 17% will have life-threatening issues as a result. Restrictive eating can include both food and fluids. Restrictive eating includes avoidance of particular foods and fluids and restricting the intake amount.

People with PANS restrict eating due to disordered sensory hypersensitivity, obsessional fears, difficulty swallowing, decreased appetite, or body image issues. For many, food restrictions are firmly rooted in OCD, a primary PANS symptom; there are often fears of contamination/poisoning, vomiting, choking, or anaphylaxis. Another symptom of PANS PANDAS is sensory processing issues; hypersensitivity can lead to problems tolerating particular textures, tastes, and smells. Some patients have swallowing issues. Doctors can order a swallowing study if there are obsessional symptoms surrounding vomiting or choking to rule out a physical issue that may be prompting fears. PANS PANDAS patients can have distorted body images, especially in patients who have had PANS PANDAS for several years, so this is seen more often in older patients, but it can happen in younger patients.

PANS patients with restrictive eating may experience significant health issues even if they have not been diagnosed with an eating disorder like Avoidant Restrictive Food Intake Disorder (ARFID) or Anorexia Nervosa (AN). Note that PANS patients with GI issues or stomach pain should discuss causation and treatment with a doctor. Both Lyme and Strep can lead to GI pain, so take care to consider causes.

Increased awareness of eating disorders resulting from PANS is needed to provide proper diagnosis and treatment promptly. Treating PANS/PANDAS is a three-pronged approach: 1) remove the source of inflammation, 2) treat the dysregulated immune system and inflammation 3) treat the symptoms. If PANS patients with eating disorders are not diagnosed correctly, then they are not receiving all three prongs of the PANS PANDAS treatment guidelines; only implementing psycho-therapeutic interventions will not be enough for lasting recovery.

WHAT ARE **PANS & PANDAS**

PANS Pediatric Acute-onset Neuropsychiatric Syndrome

PANS is a clinical diagnosis based on history and physical examination. PANS diagnostic criteria require an acute onset or sudden worsening of OCD and/or restrictive eating, with concurrent symptoms in at least two of seven neuropsychiatric and somatic categories. Infections, metabolic disturbances, other inflammatory reactions, and stress can trigger PANS. Infectious triggers include upper respiratory infections, influenza, strep, mycoplasma pneumoniae, and Lyme borreliosis, among others. The average age of onset is between 3 and 13, but post-pubertal cases do occur. There is no requisite age of symptom onset for a PANS diagnosis.

PANS
is caused by an infectious trigger or other non-infectious agents.

PANDAS Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

PANDAS, a subset of PANS, is associated with group A Streptococcus (GAS) infections. Not all patients have a positive strep throat culture, and examination must be followed by ASO and ADB immune responses. The onset of symptoms can occur within days of contracting strep, or within several months.

PANDAS
is associated with group A Streptococcus (GAS) infections.

PANS/PANDAS are misdirected immune responses, often with an encephalitic onset, resulting in acute onset of OCD, tics, and/or restricted food intake, along with other neuropsychiatric and somatic symptoms. After the initial onset, PANS/PANDAS symptoms follow a relapsing/remitting course. Initial triggers may differ from secondary triggers. During each recurrence, symptoms can worsen, and new symptoms may manifest. Symptoms can range from mild to severe. In mild cases, children might function well enough to continue to attend school. In severe cases, symptoms can become life-threatening due to extreme food restriction and/or suicidality. Many children with PANS/PANDAS are diagnosed with a psychiatric illness and prescribed psychotropic medications rather than evaluated and treated for an underlying infection. According to a consortium of experts convened by the National Institute of Mental Health, appropriate treatment for these disorders is a triad that incorporates psychological support (CBT, ERP, and/or psychotropic medication), antimicrobial treatment, and immunomodulation.

PANS PANDAS **DIAGNOSTIC EVALUATION & TREATMENT GUIDELINES**

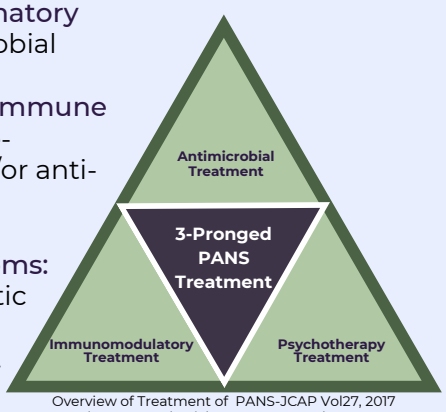
Diagnostic Criteria for PANS

- Abrupt, acute onset of
  - Obsessive-Compulsive Disorder or
  - Severely Restricted Food intake
- Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven following categories:
  1. Anxiety, separation anxiety
  2. Emotional lability or depression
  3. Irritability, aggression, and/or oppositional behaviors
  4. Behavioral or developmental regression
  5. Deterioration in school performance
  6. Sensory or motor abnormalities, tics
  7. Somatic signs: sleep disturbances, enuresis, or urinary frequency
- Symptoms are not better explained by a known neurologic or medical disorder
- Age requirement – None

Three Modes of Treatment

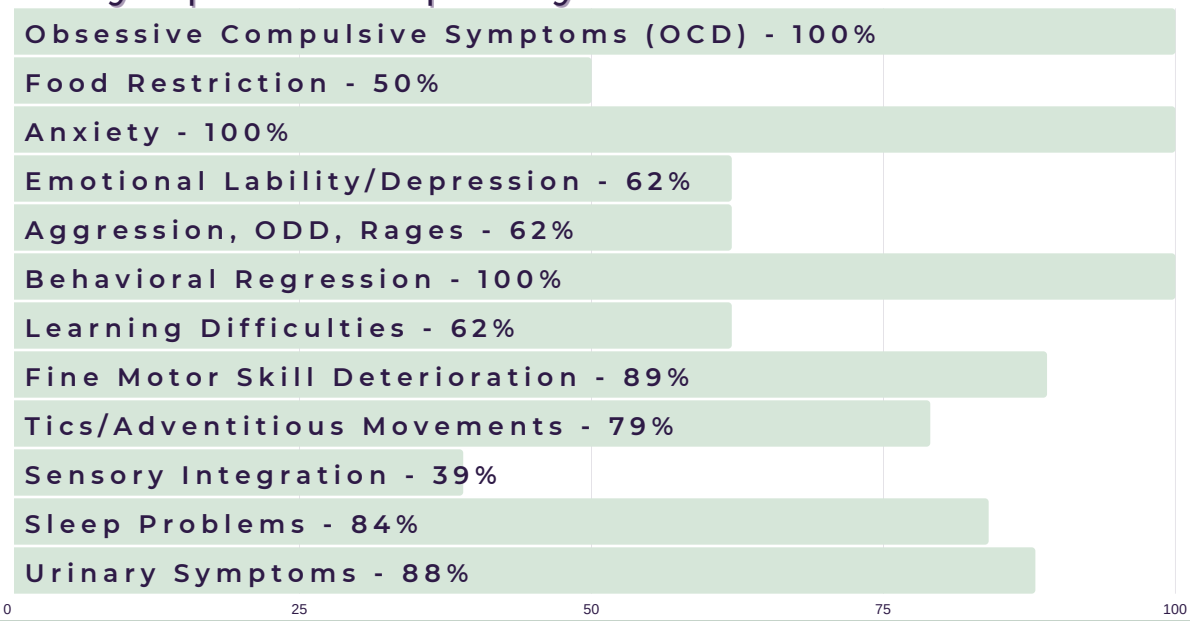
"Treatment of PANS involves a three-pronged approach that utilizes psychiatric medications when appropriate to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation, and anti-inflammatory and immune-modulating therapies to treat disturbances of the immune system."

- Remove inflammatory source: antimicrobial treatments.
- Treat disrupted immune system: immune-modulating and/or anti-inflammatory interventions.
- Alleviate symptoms: psychotherapeutic treatments, psychotherapies.



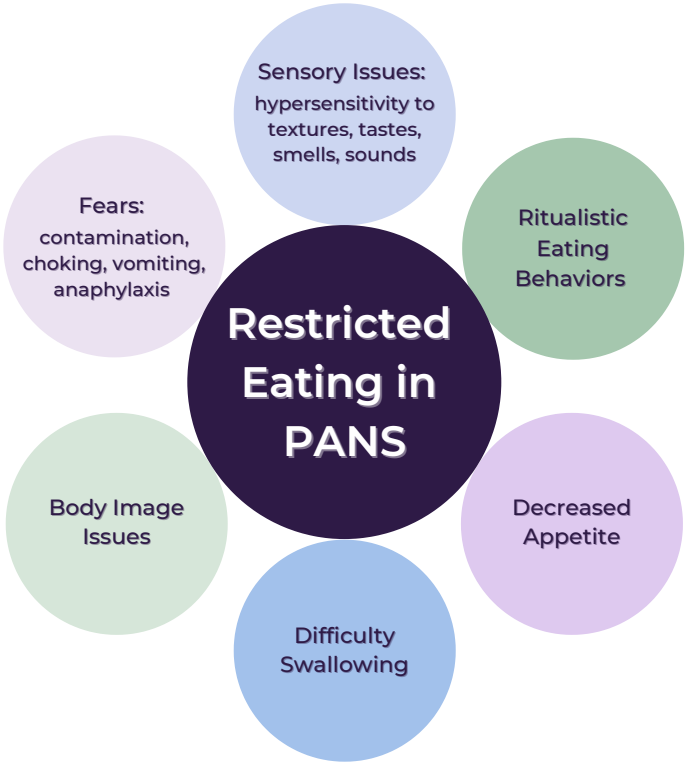
Overview of Treatment of PANS-JCAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

PANS Symptom Frequency



RESTRICTIVE EATING **in PANS PANDAS**

Brief Overview



- Can include foods and fluids
- Typical Reasons
  - Sensory processing issues: hypersensitivity to textures, tastes, smells, sounds
  - Fears: contamination, poisoning, choking, vomiting, anaphylaxis
  - Ritualistic eating behaviors
  - Difficulty swallowing
  - Decreased appetite
  - Body image issues
- Can have a comorbid diagnosis of
  - Avoidant Restrictive Food Intake Disorder (ARFID) is the diagnosis most seen
  - Anorexia Nervosa also possible, though usually PANS patients are not worried about body shape or size, but it is thought this rate increases the longer symptoms persist
  - Unlikely to meet the criteria for Binge Eating Disorder (BED) but excessive eating does occur

In youth with PANDAS, food restriction has been reported to occur in the context of obsessional fears about contamination, as well as in the context of the sudden onset of fears of swallowing, choking, or vomiting that are often associated with sensory phenomena (e.g., the perceived texture or appearance of the food.

Disordered Eating and Food Restrictions in Children with PANDAS/PANS. Toufexis, DO, et al. JCAP Vol 25, 2015

IMPORTANCE OF **THE RIGHT DIAGNOSIS**

Identify When Restrictive Eating is Due to PANS

- The therapies for PANS cases are different from those with non-PANS-related ARFID or AN since antibiotics and/or immunomodulatory treatments can be curative. Treatment should consist of the full PANS PANDAS three-pronged treatment approach; treating only psychotherapeutically would more than likely not be sufficient.
  - Eating disorder specialist or other targeted therapeutic interventions may be needed in cases of severe symptoms or residual restricted eating
- Can cause malnutrition, nutritional deficiency
- Can cause medical complications
- Can cause significant weight loss or failure to gain weight
- Can cause psychosocial functioning issues & developmental delays
- Can cause gastrointestinal complications

Risk of Medical Issues Increase With

- Rapid weight loss
- Significant weight loss in proportion to body size
- Extended periods of restricted eating
- Extreme restriction of fluids or food

Medical Work Up for Other Medical Disorders

A thorough medical evaluation should be performed to rule out additional medical disorders due to restricted intake of food and/or fluids.

- Rule out other medical disorders (e.g., eosinophilic esophagitis, structural or neurological causes of dysphagia, and nausea), include a swallowing study if there are fears of choking or vomiting
- Assess for medical instability
- For severely limited intake, assess orthostatic vital signs, EKG, and electrolytes, including phosphorus and magnesium, and monitor for refeeding syndrome
- Hospitalization may be required if medically unstable

Other Eating Disorders

Eating restrictions as a result of PANS PANDAS is not merely picky eating. There are distinct differences between picky eating, ARFID, and Anorexia Nervosa. Please see ASPIRE website for further details.

Picky Eating

- Typically starts 18 months-3 years
- Typically outgrows by age 6
- Continues to like eating
- No fear of swallowing or choking
- Doesn't change social eating activities
- Diet changes due to a matter of control, typically choosing what they enjoy
- Certain foods preferred for periods of time
- Usually accepts more than 30 foods
- Typically no associated medical issues

ARFID

- Onset 4-13 but can start earlier
- Due to: lack of interest in eating, sensory avoidance, fear of negative consequences (choking, illness, etc)
- Will stop social eating activities
- Higher rate of males
- Increased rate of anxiety
- Feeding Tube: often accepted more often, accept calorie content
- High rate of comorbid medical issues – GI issues, swallowing disorder, food trauma, oral-motor delay
- Usually accepts less than 20 foods

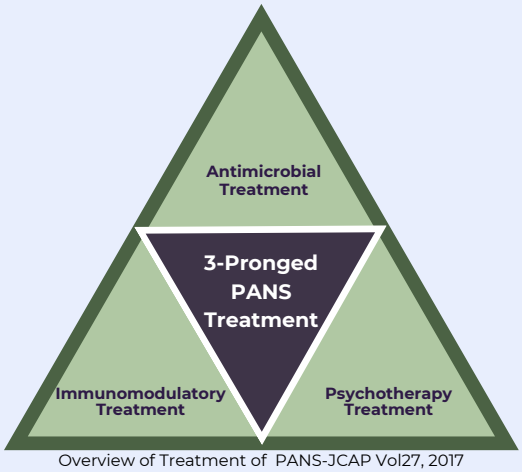
Anorexia Nervosa

- Onset 13-15
- Due to: distorted body image. Fear of weight gain
- Higher rate of females
- Increased rate of depression
- Feeding Tube: often intolerant, don't accept calorie content
- Low rate of comorbid medical issues

TREATMENT **OVERVIEW**

PANS PANDAS treatment is dependant on a three-pronged approach: 1-remove the source of inflammation with antimicrobials (if triggered by an infection), 2-treat the dysregulated immune system with immune modulators and/or anti-inflammatories depending on severity, 3-treat symptoms psychotherapeutically as needed. Antibiotics, IVIG, and/or steroids may improve symptoms of bacterial infection-triggered anorexia nervosa quickly. However, patients with continuing eating abnormalities will need medical interventions and psychotherapeutic treatments to focus on factors contributing to the eating restrictions. Patients with insufficient nutrition leading to poor growth or weight loss must be treated aggressively to minimize increased psychological and medical complications. The duration and severity of restricted eating due to PANS can vary from patient to patient and from flare to flare. See ASPIRE website and toolkits for more information on PANS PANDAS treatment.

PANS Three-Pronged Treatment Guidelines

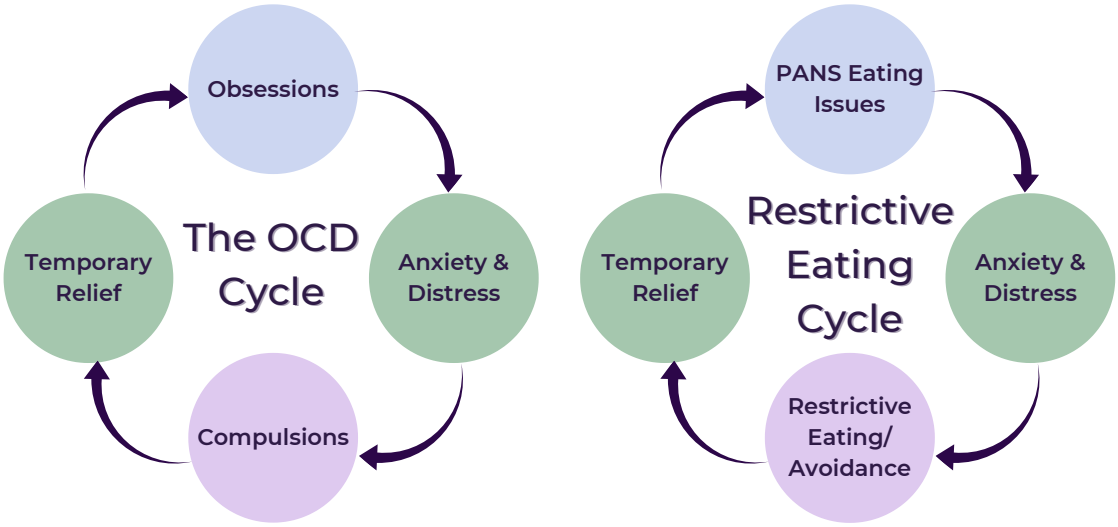


Overview of Treatment of PANS-JCAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

- Treat PANS PANDAS as per three-pronged PANS treatment recommendations (See page 3 & ASPIRE website & toolkits)
- Treat the source of inflammation
- Treat the dysregulated immune system
- Focus on maintaining adequate nutrition and hydration while treating underlying brain inflammation
- Medical work up to assess for other medical disorders
- During the acute phases feeding tubes may be necessary
- Feeding Therapy to target factors contributing to ongoing restricted intake
  - Exposure and Response Prevention (ERP) for compulsive behaviors and anxiety
  - Gradual exposure to situations and food which cause fear in a safe environment
- Incremental progress to increase intake & expand diet
- CBT & ERP to address obsessive, intrusive thoughts
- Occupational Therapy (OT) to address breathing, relaxation, posture may help fear
- Family Therapy to educate and empower families to firmly support goals, to lift blame from the parents, and help build compassion

Restrictive Eating Cycle

In OCD, there is a loop of obsessive thoughts leading to anxiety that prompts a compulsion, which only provides temporary relief before the intrusive obsessive thoughts dominate again. This vicious cycle is similar to what we may see with restrictive eating restrictions due to PANS. Restrictive eating seen in PANS due to fears, ritualistic behaviors, swallowing issues, or sensory issues may create a vicious cycle. Someone with PANS has their initial reason for avoiding foods or restricting intake, which causes anxiety, then there is temporary relief from not eating, but this reinforces the reasons behind these choices.



CBT & ERP Therapy for Restricted Eating

Exposure and Response Prevention (ERP) and Cognitive Behavioral Therapy (CBT) are used in treating ARFID and can be applied to treating patients with PANS PANDAS who have restricted food or fluid intake. ERP may be helpful for compulsive behaviors and anxiety. ERP involves gradual exposure to situations and food which cause fear and anxiety but in a safe and controlled environment. The patient makes incremental progress towards increasing intake and expanding diet. CBT may be helpful to address obsessive, intrusive thoughts. ERP helps remove the fear connected to particular foods. The approach involves rewards for taking small bites of anxiety-inducing food. It also includes talking about and journaling about foods, learning coping skills, and mental visualization. CBT uses talk therapy to help recognize and correct self-destructive patterns of thought and behavior. It can also address other OCD behaviors, anxiety, and depression.

Treatment Goals

- Achieve/maintain a healthy weight
- Correct nutritional deficiencies
- Eat foods the five basic food groups
- Be more comfortable eating in social situations

Treatment is Not...

- Attempting to change your personality
- Eating unusual foods
- Force-feeding

1 Learn & Make Early Changes

- Work on determining why food restrictions happen: track situations, triggers, food choices,
- Increase intake of preferred foods
- Begin to increase variety

2 Continue Changes & Set Big Goals

- Increase amount of food
- Increase food variety
- Establish goals to face fears

3 Face Fears

- Begin exposure by starting small and gradually increasing
  - Exposure to new foods
  - Exposure to feared foods

4 Prevent Relapse

- At the completion of the program, create plans to continue practicing at home to prevent relapse

Thomas, J.J. and Eddy, K.T. (2019). Cognitive-Behavioral Therapy for Avoidant/Restrictive Food IntakeDisorder: Children, Adolescents, & Adults. Cambridge: Cambridge University Press.

Family Therapy

Family therapy as used in anorexia nervosa may also be applicable in restricted food intake seen in PANS PANDAS or ARFID. Family therapy focuses on increasing education on the risks of restrictive eating while empowering parents to focus on and be firm about weight gain and nutrition goals. Family therapy also serves to lift blame from the parents and helps build compassion and understanding of the patient's experience. Families may learn to maintain detailed food diaries and use weight graphs.

Strategies for School

One can include accommodations and goals for restrictive eating in an IEP. Feeding therapy is a related service for an IEP as per case law and guidance from OSEP. Feeding therapy support at school is essential if the family does not have a private feeding or cognitive-behavioral therapist. If one has a private therapist, communication between the doctor, therapists, the school, and family is critical. Some families and private feeding therapists may feel that providing supports instead of creating goals at school and then working on goals outside of school may be more effective. The key is to be consistent in approach. Eating disorders and the therapy can be stressful enough; the addition of other PANS symptoms can be overwhelming. It may be more appropriate to focus on socialization and fun and provide a break during lunch rather than implementing feeding therapy during lunch. Also, it may be more effective to master strategies at home before generalizing to the school environment.

- Communicate with family, providers, and therapists about specific therapeutic strategies
- Be flexible about the time it takes to eat - May need longer breaks
- Do not draw attention when a student eats the same foods repeatedly
- Allow frequent snacks to ensure adequate calories
- Be flexible on healthy food school policies if a student is self-restricted to foods not on the list
- Do not pressure to eat more or take a bite
- Provide anytime pass or alternate activity if a student's restrictive eating prevents them from participating in food-related activities
- Provide anytime pass to access the bathroom

RESTRICTED EATING **STUDIES HIGHLIGHTS**

Prevalence of PANS in Child and Adolescent Eating Disorders

Marya Aman, Jennifer Coelho, BoyeeLin, Cynthia Lu, Shannon Zaitsoff, John Best and S. Evelyn StewartBC Children's Hospital Research Institute, University of British Columbia.

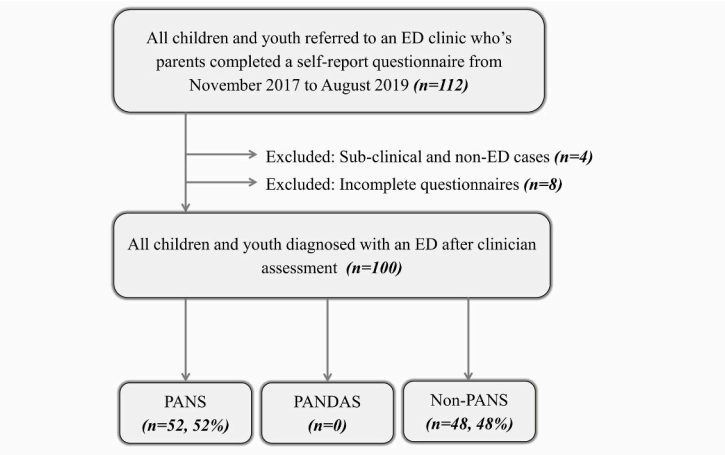


FIG. 1. Sampling methodology used to determine prevalence of PANS and PANDAS in a pediatric ED outpatient clinic.

ED, eating disorder; PANS, pediatric acute-onset neuropsychiatric syndrome; PANDAS, pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections.

Conclusion

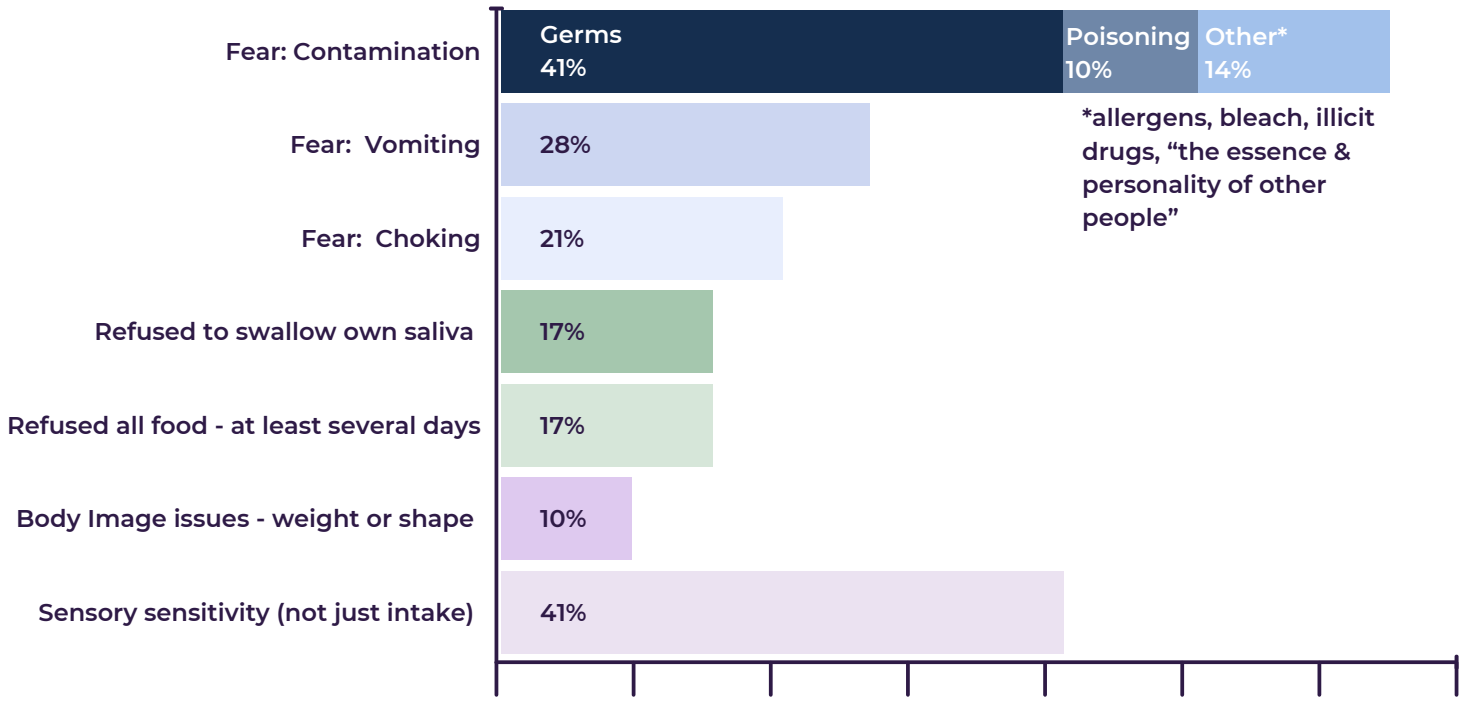
- "The surprisingly high lifetime PANS rate of 52% within pediatric ED was higher than that previously reported for OCD populations. The large majority had an abrupt onset of parent-reported OC symptoms as well as abrupt food restriction.
- Those in the PANS group were more likely to be female, be prescribed an SSRI, and have parent-reported abrupt OC symptom onset, abrupt food refusal, relapsing and remitting course, and concurrent anxiety, depression, irritability or aggression, behavioral regression, school deterioration, and sleep problems, enuresis, and/or frequent urination.
- This appears to be a distinct subgroup that requires further characterization with respect to functional impacts and management approaches."

PANS PANDAS with Food Restrictions and Disordered Eating

Disordered Eating and Food Restrictions in Children with PANDAS/PANS. Toufexis, DO, et al. JCAP Vol 25, 2015. DOI:10.1089/cap.2014.0063

"In youth with PANDAS, food restriction has been reported to occur in the context of obsessional fears about contamination, as well as in the context of the sudden onset of fears of swallowing, choking, or vomiting that are often associated with sensory phenomena (e.g., the perceived texture or appearance of the food." The study included 29 children with PANS who had new abrupt onset of eating restriction or food avoidance, ages 5-12 years old. The children met the criteria for ARFID. Most "had a paralyzing fear of some adverse consequence of eating normally," believing they would vomit or choke, and the food was contaminated. The three children, who expressed concerns about "getting fat" or body image, developed those thoughts later.

The rate of eating disorders in children is increasing, especially in males. “Between 1999 and 2006, there was a 119% increase in eating disorder-related hospitalizations for children < 12 years of age.” This increase may be linked to PANS. The authors of the study hope that a PANS diagnosis will be considered in cases with an acute-onset food restriction or avoidance. The therapies and outcomes for PANS cases are different from those with ARFID or AN since antibiotics and/or immunomodulatory treatments can be curative.



Characterization of the PANS Phenotype

Murphy TK, Patel PD, McGuire JF, et al. Characterization of the pediatric acute-onset neuropsychiatric syndrome phenotype. J Child Adolesc Psychopharmacol. 2015;25(1):14-25. DOI:10.1089/cap.2014.0062

The study included 43 children with PANS and OCD, ages 4-14 years old.

- 47% had food restriction
- 23% (10) significant impairment related to food restriction (i.e., weight loss, dehydration, and/or hospitalizations), met criteria for ARFID
- 1 had food-related OCD symptoms only
- 9 had OCD symptoms related to food and other issues
- Reason for Food Restriction
  - Food-related OCD symptoms included contamination from germs and/or toxins, poison, fear of vomiting, choking
  - Fear of weight gain

Case Study of a Child with Anorexia Nervosa & PANS PANDAS

Clinical Case Rounds in Child and Adolescent Psychiatry: Certain Eating Disorders May Be a Neuropsychiatric Manifestation of PANDAS: Case Report. Cynthia V. Calkin MD; Carlo G. Carandang MD, ABPN (Dip) J Can Acad Child. Adolesc Psychiatry. 2007 Aug; 16(3): 132–135. PMID: 18421369

"This case suggests that EDs, in some cases, may be an autoimmune-mediated neuropsychiatric manifestation or clinical sub-type of PANDAS. The patient in our case rapidly recovered from his ED and OCD. Perhaps by considering the proposed pathophysiology of PANDAS and by targeting the management of future GABHS infections, the usual course of EDs and OCD could be altered in patients believed to have an autoimmune etiology."

- Eight-year-old with PANDAS, OCD, Anorexia Nervosa (AN)
- Recurrent GAS infections
- OCD symptoms not confined to the Eating Disorder (ED)
  - Avoided certain foods after being taught about healthy eating at school
  - Body dysmorphia: looked in the mirror and expressed concerns about his weight
  - Contamination fears: determined that only packaged foods were safe
- ED symptoms were not exclusively OCD-based.
- Significant weight loss over a 2 month period
  - Only ate 200 calories a day
  - Lost 8kg of weight
  - Hospitalized at 75% of his ideal body weight
- After 2nd strep infection, developed tics and obsessive-compulsive rituals before eating
  - Cited compulsions helped him relax and distracted him from images in his head
  - Intrusive thoughts & compulsion of doing hand movements or the food will poison him
  - Intrusive thoughts - thought his mother was a criminal for contaminating his foods
  - He would only walk on one side of his father as not to "give off (his) fat cells"
  - Other OCD behaviors separate from food-related obsessions
  - CY-BOCS score of 33 - extremely severe OCD
- Treatment included
  - First - refeeding via ED protocol, CBT, psychiatric medications - one tolerated, one not tolerated
  - After subsequent flares - given clarithromycin - started to gain weight, CYBOCS went down to 19 - moderate OCD, choreoform-like movements stopped
    - After five weeks on clarithromycin - no OCD and not engaging in ritualistic behaviors
  - At normal weight - had a tonsillectomy and remained stable for 11 months

Case Study Anorexia Nervosa, OCD & Strep

Anorexia, OCD, and streptococcus. Henry MC, Perlmutter SJ, Swedo SE. J Am Acad Child Adolesc Psychiatry. 1999 Mar; 38(3):228-9. DOI: 10.1097/00004583-199903000-00002

Describes three cases of GABHS-triggered OCD in with obsessional fear of eating. In the first case, the child had typical OCD symptoms followed by a fear of fat contamination, leading to more common AN symptoms. In the second case, a 7-year-old boy had an abrupt onset of fear of eating after choking on pizza. He had a positive throat culture but with no pharyngitis, but antibiotics did not help. Then his OCD included excessive hand-washing and contamination obsessions; behavioral therapy helped. Later, after his sister had positive throat culture, he had an abrupt exacerbation of OCD symptoms. In the third case, a 6-year-old girl, one week after GABHS pharyngitis, developed a fear her food was contaminated. After symptoms did not resolve with an antibiotic, three weeks later, she was hospitalized and improved with sertraline and behavioral therapy. Then she had confirmed strep throat leading to another flare of abrupt contamination obsession. Antibiotics improved symptoms until she had a repeated PANDAS flare.

Case Study Infection-triggered Autoimmune Subtype of AN

Case study: an infection-triggered, autoimmune subtype of anorexia nervosa. Sokol MS, Gray NS. J Am Acad Child Adolesc Psychiatry. 1997 Aug; 36(8):1128-33. DOI: 10.1097/00004583-199708000-00021

The first case describes a 12-year-old boy whose AN worsened one month after an untreated severe upper respiratory tract infection with a negative throat culture but had elevated ASO and anti-DNase-B titers. Antibiotics alleviated his AN. The second case describes a 16-year-old boy who, after a series of URIs, had sudden OCD and failure to gain weight as he grew taller. He had a history of repeated GABHSpharyngitis and had an elevated anti-DNase-B titer. His symptoms resolved after a few months without treatment.

Use of IVIG for PANS PANDAS

Use of Intravenous Immunoglobulin in the Treatment of Twelve Youths with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. Miro Kovacevic, MD, Paul Grant, MD, and Susan E. Swedo, MD - JCAP Vol 25, No 1, 2015 - DOI: 10.1089/cap.2014.0067

Abstract

This is a case series describing 12 youths treated with intravenous immunoglobulin (IVIG) for pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS). Although it is a clinically based series, the case reports provide new information about the short-term benefits of IVIG therapy and are the first descriptions of long-term outcomes for PANDAS patients.

Patient A - 7.5-year-old girl

- OCD - intrusive thoughts, contamination fears (urine, saliva), repetitive compulsions, reassurance seeking
- A need to remember what foods she ate looked like, and avoidance of foods she feared she would not remember
- Treatment: antibiotics, IVIG, steroids, CBT, and several relapses, 4 years later doing very well

Patient D - 9.5-year-old boy

- Fear of choking and chronic abdominal pain
- Led to food refusal
- Led to a 4.5 kg (20%) weight loss
- Hospitalization, and tube feedings
- Symptoms for 1 year prior to treatment
- Treatment: prednisone, IVIG, and prophylactic antibiotics resulting in full remission for a year at the time of follow-up

Patient G - 9-year-old boy

- Sudden onset OCD, anxiety, and tics
- Later developed more severe sudden onset severe PANS symptoms - compulsive, recurrent vomiting of all foods and liquids, including water
- Led to a 7 kg weight loss
- Diagnosed with postinfectious gastroparesis, fed exclusively via a nasojejunal tube
- Treatment: steroid burst - temporary improvements
  - First round of IVIG - dramatic improvement - resumed normal food intake orally, removal of his nasojejunal tube. Had residual vomiting without weight loss but interfered with normal life.
  - Second round of IVIG led to complete remission which held through the three-year follow-up

Patient L - 8-year-old boy

- OCD, other PANS symptoms, several ill-defined abdominal complaints
- Gastroenterological evaluation - negative results
- Eventually led to complete refusal to eat
- Led to nearly 25% of his body weight (declining from 22 kg to 17 kg)
- Hospitalized numerous times for tube feedings and psychiatric interventions
- Treatment: Several SSRIs showed no benefit. Amoxicillin - small improvement in symptoms & stabilized weight loss
  - Steroids & IVIG - significant improvements including eating at a previously unacceptable restaurant and ate without difficulty
  - Second round of IVIG needed after progress stalled but recovery has held firm since

Conclusions:

This case series demonstrates the benefits of IVIG therapy for youths with PANDAS/PANS, including those who had been symptomatic for several years prior to treatment. Although the generalizability of this retrospective report is limited, the selected cases represent the breadth of symptom presentations in PANDAS/PANS and provide additional evidence that IVIG may be useful in the management of children with moderate-severe symptoms.

ASPIRE
ALLIANCE TO SOLVE PANS & IMMUNE-RELATED ENCEPHALOPATHIES

Our Mission
To improve the lives of children and adults affected by PANS, PANDAS, and immune-related encephalopathies.

Our Vision
We aspire to create a world where children and adults affected by PANS, PANDAS and related encephalopathies obtain a timely diagnosis from informed providers and receive effective, proven and affordable treatments and support in all areas of daily living, without discrimination.

ASPIRE
Alliance to Solve PANS & Immune-Related Encephalopathies

Who We Are
We are experienced leaders in the PANS advocacy community. We are parents, providers and experts in our field who believe collaboration and empowered action are the keys to the world we seek: one where no one suffers through PANS and immune-related encephalopathies without access to a knowledgeable provider, insurance coverage for standard-of-care treatments or the support that comes with public awareness.

We work collaboratively to improve the quality of life for those affected by PANS, PANDAS and immune-related encephalopathies. We focus our efforts on empowering and connecting our community with tools and resources for advocacy, education, support, and awareness.

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