PANS/PANDAS:
From Sudden Onset to Controversies

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Agenda

- Overview of the syndrome
- The ongoing scientific debate
- Treatment guidelines
- Psychiatric assessment and intervention
- Psychological interventions
- Family accommodations and support
- Parent-based and other interventions
- Resources
- Q & A

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PANS / PANDAS: What is it?

- Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS)
- Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)
  - Syndromes as the result of autoimmune-induced neuroinflammation
    - May be considered a form of Basal Ganglia Autoimmune Encephalitis
  - Abrupt, acute onset of symptoms, typically first experienced in early youth
  - Relapsing-remitting course
  - Prevalence estimates as many as 1 in 200
  - 70% have a family history of autoimmune or strep related illness

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Constellation of Associated Symptoms

- Obsessive Compulsive Disorder
- Restrictive Eating
- Emotional Changes
- Tic Disorders/Motor Abnormalities
- Urinary Symptoms
- Sleep Disturbances
- Cognitive Changes
- Hyperactivity
- Hypervigilance
- Behavioral Regression
- Aggression/Oppositionality
- Sensory Hypersensitivity
- Academic Difficulties
- Dysgraphia
- Hallucinations

(Chang et al. 2013)

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Potential Etiology: How Did We Get Here?

- Currently considered idiopathic; however,
  - Longstanding questions about the role of infection in psychiatric disorders
  - Temporal relationship observed between tics and ocd in those with rheumatic fever and Sydenham's chorea
    - 1990s - Hypothesis that group A streptococcal infection could cause tics and/or ocd (PANDAS)
    - 1998 - Publication of the seminal paper on PANDAS
    - PANDAS has since broadened to be more inclusive of other possible triggers, including both infectious and environmental (PANS)

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Trigger Warning: The Ongoing Scientific Debate

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The Ongoing Scientific Debate

- Critics argue:
  - Questions of prevalence
  - Questions of coincidental correlation vs. causation and diagnostic overlap
  - PANDAS / PANS remains a diagnosis of exclusion
  - Questions of inadequacies of throat cultures and blood antibody tests
  - Criticisms of existing body of treatment studies

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The Ongoing Scientific Debate

- Proponents argue:
  - Decades of compelling case reports/series, and large epidemiological studies suggest associations between psychiatric symptoms and autoimmune conditions
  - PANDAS / PANS has a distinct presentation
  - Many have reported positive outcomes with treatment such as antibiotic therapy, plasma exchange (plasmapheresis) and intravenous immunoglobulin (IVIG) treatments
  - PANDAS / PANS may be viewed as a conceptual framework describing the etiological and phenotypical complexity of many psychiatric disorders
  - Large scale, randomized, placebo-controlled treatment trials are needed
  - Complex problems often require complex solutions
  - Families need help now

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Diagnosis

- Multidisciplinary assessment (and treatment) is important
  - Personal and family history
  - Medical history and physical examination
  - Medical tests (may include: EEG, swallow study, sleep study, lumbar puncture, throat culture, blood draw)
  - Neurological assessment
    - There are a number of important differential diagnoses to be considered
  - Infectious disease evaluation, when warranted
  - Assessment of immune dysregulation, when warranted
  - Genetic evaluation, when warranted
  - Psychiatric / Psychological assessment

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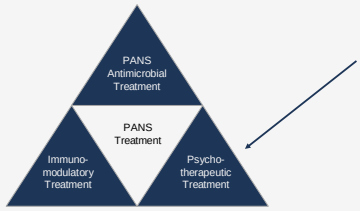
Treatment Guidelines



(Swedo, Frankovich, & Murphy, 2017)

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Psychiatric Assessment and Intervention

- Comprehensive Diagnostic Assessment
  - Personal and family history
  - Structured and unstructured clinical interviews
  - Symptom measures
  - Safety/Risk assessment
- Psychopharmacological Intervention
  - Psychopharmacological Intervention
  - Individually tailored, symptom-targeted medications
  - Selective serotonin reuptake inhibitors (SSRI) are standard of care
  - Atypical neuroleptics may be considered in severely impairing cases

(Thienemann et al., 2017)

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Psychological Intervention - Family Support

- Family support is essential
  - Psychoeducation - Provide treatment rationale, establishing expectations, course of illness, connecting families to accurate, reliable resources
  - School communication - Psychological treatment providers may assist in effective communication with school personnel and child study teams
    - Academic accommodations via 504 plans or academic modifications via IEPs
    - Behavior planning with teacher(s)
    - FBAs and/or therapeutic services available in the school setting
    - Ongoing close communication is important for monitoring and tailoring of school-based interventions due to fluctuating course of symptoms

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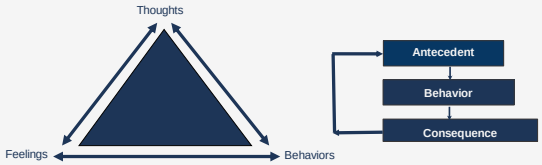
Psychological Intervention - Foundations of CBT



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Obsessive Compulsive Disorder

- Obsessions
  - Recurrent, persistent thoughts, images, or urges that are intrusive, unwanted, and distressing
  - Attempts are made to ignore, suppress, or neutralize them
- Compulsions
  - Repetitive behaviors or mental acts carried out in response to an obsession or in accordance with rigid rules
  - Aimed at reducing distress or preventing a feared outcome

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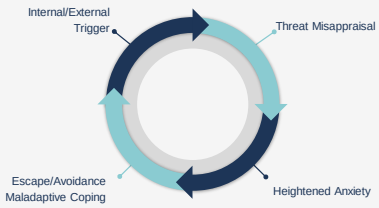
The Anxiety/OCD Cycle



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Psychological Intervention - Exposure & Response Prevention

- ERP is a systematic treatment with the individual that involves:
  - Intentionally confronting obsessive thoughts, images, and urges → (i.e., exposure)
  - Refraining from behaviors (compulsions) that avoid/resist/reduce distress → (i.e., response prevention)
- Exposure therapy facilitates new learning in which:
  - Feared outcomes are disconfirmed
  - Distress tolerance is built
  - This new learning becomes stronger with repetition via inhibitory learning
    - In other words, the more you do that which causes you distress, the easier it becomes
- Research suggests that benefits carry over to subsequent flares

(Storch et al. 2006)

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Family Accommodation of OCD and Anxiety

- No parent wants to see their child suffer
- And, they want to maintain the family's functioning, so they may:

• Provide reassurance / advice	• Facilitate compulsions
• Invite "confessions"	• Facilitate avoidance / distraction
• Modify family activities	• Assume responsibilities
• Engage in compulsions	• Negotiate/Modify expectations

- Short-term benefit, long-term cost

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Maximizing Parental Support

- Teach parents to to help their child, not their child's anxiety
- Parents eliminate reassurance and practice providing supportive statements:
  - Validation + Confidence = 
    - 🚫 "You'll be okay."
    - 👍 "I see that this is scary and hard for you, but I know you can manage these feelings."
- Parents eliminate answering anxiety and practice non-engagement responses:
  - 🚫 "It's safe." "It's ok."
  - 👍 "Okay," "Maybe," It's possible" "What do you think?" Shoulder shrugging.
- Parents practice modeling willingness, acceptance, & tolerance
- This is the toughest part - Hang in there, parents!

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Reducing Family Accommodations

- Help families to understand the ways in which accommodations maintain OCD and anxiety
  - They prevent opportunities for kids to gain confidence in their ability to tolerate anxiety, disgust, distress, and uncertainty
  - Prevents expectancy violation which is essential learning
- Collaborate with parents to gradually remove accommodating behaviors
  - Each accommodation is removed one at at time, in a systematic manner
  - Successive approximations toward the removal of an accommodation may be warranted
- Ignoring or discontinuing reinforcement of previously reinforced behavior consistently will serve to decrease the behavior

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Psychological Intervention - Parent-Based Interventions

- But, my child is not a willing participant in behavioral treatment!
  - That's okay. There are parent-based options to shape behavior and improve family functioning.
- For oppositional, aggressive, or otherwise challenging behaviors:
  - Parent-Child Interaction Therapy (PCIT) (ages 2-7, or adapted for older children ages 7-10)
    - Focus on positive, productive interaction and behavior shaping through skills practice
  - Parent Management Training (PMT) (ages 3-13)
    - Focus on behavior change through learning parenting skills related to ABCs
  - Behavioral Parent Training (BPT) (pre-teens and teens)
- Focus on implementing effective and consistent communication of rules and routines and strategies to shape behavior

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Psychological Intervention - Parent-Based Interventions

- For anxiety disorders, OCD, and restricted eating:
  - Supportive Parenting for Anxious Childhood Emotions (SPACE)
  - Goals are to systematically increase quality support and decrease accommodation
    - Find a provider at SPACEtreatment.net

(Leibowitz et al. 2013)

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Behavioral Intervention - Other Interventions

- Cognitive Behavioral Therapy (CBT)
- Comprehensive Behavioral Intervention for Tics (CBIT)
- Habit Reversal Training (HRT)
- Cognitive Behavioral Therapy for Insomnia (CBT-I)
- Behavioral Activation (BA)
- Interpersonal Therapy (IPT)
- Organizational Skills Training (OST)
- Dialectical Behavioral Therapy (DBT)
- Acceptance and Commitment Therapy (ACT)

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Resources

- Aspire - www.aspire.care
- PANDAS Network - www.pandasnetwork.org
- PANDAS Physicians Network - www.pandasppn.org
- International OCD Foundation - www.iocdf.org
- National Institute of Mental Health - www.nimh.nih.gov
- Anxiety and Depression Association of America - www.adaa.org
- Association for Behavioral and Cognitive Therapies - www.abct.org

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