

Beyond the Infection:

Recovery from Pediatric Acute-Onset Neuropsychiatric Syndromes

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Background

- Onset of some pediatric neuropsychiatric syndromes (e.g., OCD, Tics) is temporally related to infection
- Leading to the proposed autoimmune syndromes PANDAS and later PANS
- Recovery from PANDAS/PANS has both similarities and differences from that of other forms of OCD & Tics
- This presentation will discuss issues involved in recovery from PANDAS/PANS and resources available to children & their families



Topics to be Covered

- I. OCD, Tics, & Associated Disorders
- II. History & Definition of PANDAS/PANS
- III. Treatment
- IV. Issues & Resources



OCD, Tics, & Associated Disorders



What is OCD?





2 main features of OCD

1. **Obsessions**
2. **Compulsions**

Obsessions

- ↑ anxiety/distress
- Can be about external situations or internal experiences



Obsessions can involve:

- **External Triggers**

e.g., “contaminated” objects, tasks involving responsibility, asymmetry

- **Internal Triggers**

e.g., intrusive thoughts, urges, or images about sex, violence, or blasphemy/immorality

Compulsions

- ↓ anxiety/distress
- Can be behavioral or mental action



Form of compulsion can be:

1. Behavioral

e.g., washing, checking, reassurance-seeking, repeating, straightening, aligning, correcting, or evening things

2. Mental

e.g., counting, thought or image replacement, prayer, mental checking, figuring-it-out



OCD in Kids

- Fears tend to be vague
- Fear often expressed as a feeling: “yucky,” “not right,”
- Anxiety expressed indirectly: “need a glass of water,” “tummy hurts”
- Distress often expressed as intolerance, “I can’t stand that”
- Aggressive behavior sometimes present, but secondary to OCD



What are Tic Disorders?



Tics

- Tic: a sudden, rapid, recurrent, non-rhythmic stereotyped motor movement or vocalization.
- 2 types:
 - 1) Motor (eye blinks, head jerks, mouth movements, etc.)
 - 2) Vocal (grunts, sniffing, coughing, words)
- Can be “Simple” or “Complex”



Tic Disorders

- Provisional (Transient) Tic Disorder
 - either type of tic less than a year
- Persistent (Chronic) Motor or Vocal Tic Disorder
 - Motor or vocal tics for more than a year
- Tourette's Disorder (Tourette Syndrome)
 - Motor and vocal for more than a year
- Tic Disorder, NOS



Can Other Problems Accompany the OCD or Tic Disorders?

Comorbidity in Childhood OCD

CONSECUTIVE SERIES (N=112)

	<u>N</u>	<u>%</u>
Other Anxiety Disorders	47	42.0
ADHD	22	19.6
ODD/CD	10	8.9
Tic Disorders	12	10.7
MDE/Dysthymia	12	10.7
One Comorbid Disorder	82	73.2
Multiple Comorbid	35	31.3



History & Definition of PANDAS & PANS



Original term: PANDAS

- Pediatric Autoimmune Neuropsychiatric Disorders
Associated with Streptococcus

Theory: infection triggers autoimmune reaction producing antibodies that interfere with area of brain (basal ganglia) responsible for motor behavior

Current term: PANS

- Pediatric Acute-Onset Neuropsychiatric Syndromes

Focus on unique & universal feature of symptom presentation (rapid, acute onset); recognizes other potential triggers (infections and otherwise)

PANS

- Dramatic childhood onset of OCD
- Occurring with:
 - Behavioral Regression
 - Phobias especially those around eating
 - Urinary symptoms (frequent urination or enuresis)
 - Sensory issues
 - Motor regression-eg. worsening handwriting
- Symptoms are not explained best by psychosocial, medication reactions or metabolic disorder



Characteristics

- Younger age of onset for OCD
- Onset is dramatic to the extent that the child functions at a level that is very different and frightening to the family
- Frequent association with ADHD symptoms
- Comorbid symptoms such as severe emotional lability (*meltdowns and aggression*), separation anxiety, change in school performance, bedtime fears, compulsive urination, food phobias



Possible infectious triggers

- Group A streptococcus (tonsillitis, strep throat, etc)
- Mycoplasma (bacteria that causes respiratory symptoms and walking pneumonia)
- Lyme's disease (secondary to bites from ticks typically found in the Northeast)
- Viruses—less reported but influenza A
- ?? Others



Treatment



Evaluation

- Comprehensive medical evaluation
 - Medical Examination
 - Assess for possible triggers
 - Throat Culture, consider close contacts
 - Assess for medical causes (the level of diagnostic testing is dependant on level of severity and regression)

Immunologic Intervention

- Antibiotic trials
 - Studies with small n and most of short duration, and/or inadequate control groups
 - Active comparator trial of long term prophylactic treatments showed decrease symptom flare ups
 - Issues exist with case definition and duration of symptoms as well as type, dose and duration of antibiotic treatment
 - However, many anecdotal reports do suggest improvement in symptoms
- IVIG (Intravenous Immunoglobulin)
 - Controlled trial w/ n=10 on IVIG (Perlmutter 1999)
 - Anecdotal reports
 - New NIH IVIG trial enrolling
- Plasmapheresis
- Steroids—mixed, case reports
- Montelukast (brand name: Singulair; leukotriene inhibitor)-observed to make OCD worse



Non-Immunologic Treatments for OCD & TD

- Cognitive Behavior Therapy
 - OCD: Exposure & Response Prevention
 - TD: Habit Reversal, CBIT
- Medication
 - OCD: primarily SSRIs
 - TD: Neuroleptics, antihypertensives
- Occupational therapy may be helpful for fine motor skills



Issues



Issues: For the Child

- Immediate effect of symptoms:
 - distress
 - interference with functioning
 - reduction in positive reinforcement
- Secondary effects:
 - Shame, guilt, embarrassment, anger, frustration
- Especially with PANS: Feeling out of control, confused, frightened by the suddenness and magnitude of change



Issues: For the Siblings

- Direct interference with their lives
- Conflicts with OCD sufferer
- Feeling neglected
- Resentment - the OCD sufferer gets away with things
- Fear – of the OCD sufferer’s behavior; or “could this happen to me?”
- Embarrassment, shame



Issues: For the Parents

- Indirect impact
 - Anxiety about child/family's welfare,
 - Guilt, indecision
- Direct impact
 - Disruption of personal life
 - Disruption of family life
 - Conflicts with OCD sufferer
 - Dealing with sibling issues
 - Threats to safety
 - Dealing with the school, academic issues
- Special challenge with PANS
 - Emergent nature of the situation
 - Having to adapt rapidly



Additional Burdens for Parents

- Challenge of finding proper treatment can be formidable for OCD/TD
- Extra challenges for PANS:
 - An even smaller pool of knowledgeable providers
 - Navigating the pursuit of treatment
 - Differences of opinion in the field
 - Treat the PANS, the OCD/TD, or both?
 - When & how to switch or combine approaches?
 - Evaluating risks & benefits of treatment options



Resources



Relevant National Organizations

- International OCD Foundation
especially: www.ocdfoundation.org/ocdinkids
- Anxiety and Depression Association of America
- OCD & Parenting Online Support Group
- Tourette Syndrome Association
- PANDAS Network
- PANDAS Physician Network



Additional Sources of Information

- Special issue of the *Journal of Child and Adolescent Psychopharmacology* on PANS: February 2015, Volume 25.
- FAQs about PANDAS, National Institute Of Mental Health (<http://www.nimh.nih.gov/health/publications/pandas/index.shtml>)



Local, Regional Resources

- **Advocacy, Information, & Support**
 - St. Louis OCD Support Group
 - OC Anonymous
 - Midwest PANDAS/PANS Parent Association
- **Treatment**
 - Center for OCD & Anxiety-Related Disorders, Saint Louis Behavioral Medicine Institute
 - Child & Adolescent Psychiatry Services, Washington University
 - Tracy Fritz, M.D, Family Medicine,. St. Louis, MO
 - Michael Cooperstock, M.D., Pediatrics, Columbia, MO



Conclusion

- More research needed:
 - What factors are necessary for the development of PANS?
 - Is this one syndrome or a collection of syndromes with differing feature and causes?
 - Which treatments will be effective for which individuals?
 - Can we identify ways to predict and perhaps prevent PANS?
- In the meantime, standard OCD/TD treatments and immunologic therapies offer hope of a better life to many children and their families.



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