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)**

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UCLA Child OCD Program
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 (basil 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 Immunoglobin)**
  - Controlled trial w/ n=10 on IVIG (Perlmutter 1999)
  - Anecdotal reports
  - New NIH IVIG trial enrolling

- **Plasmapherisis**

- **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

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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