CBT for PANS/PANDAS

Eric A. Storch, Ph.D.

All Children’s Hospital Guild Endowed Chair and Professor

University of South Florida
Treatment options remain unclear...

- Pharmacological treatments for PANDAS/PANS include:
  - Intravenous immunoglobulin and plasma exchange associated with significant reductions on Y-BOCS (Perlmutter et al., 1999)
    - Ongoing NIMH trial
  - Several studies have evaluated antibiotic treatment (Garvey et al., 1999; Snider et al., 2005; Murphy & Pichichero, 2002)
    - Supporting clinical accounts of acute therapy
    - Results have been mixed overall
      - Further examination is needed
What about CBT?

- Cognitive-behavioral therapy (CBT), alone or in combination with sertraline, is first line OCD treatment (POTS, 2004)

- CBT is associated with immediate and sustained improvements in family-based CBT (Barrett et al., 2004; Franklin et al., 2011; Storch et al., 2007)
The Role of CBT in PANS/PANDAS?

- Reduce acute impairment and symptomology
- Prepare and empower parents and child for potential future symptom exacerbations
How CBT Differs in PANS/PANDAS

- It generally does not...

- However, you have to consider potential factors:
  - Symptom severity
  - Dramatic nature of symptoms and associated clinical characteristics
  - Family factors
  - Potential for future symptom exacerbations
Symptom Severity

- Symptoms may be extremely severe shortly after an exacerbation/onset

- Determine timing of intervention
  - The therapist needs something to ‘grab’ onto

- May have to move a bit more slowly in treatment (or take longer)
Nature of Symptoms

- Clinical characteristics may impact outcome that need to be considered
  - Insight
  - Comorbidity
  - Motivation
Dramatic onset of families changes family functioning dramatically
   - Consider how the parent/family is doing

Treatment model is to train “parents as therapists”
   - Address family accommodation in the course of treatment
     - Include on treatment hierarchy as appropriate
   - Always include parents in session
Potential for Future Exacerbations

- Although good probability for response, symptoms may return

- CBT provides family with a tool set for addressing such occurrences
  - Empowering families so they don’t live in angst
  - Able to sort out what to do next should symptoms return

- May reduce severity of future episodes
Dramatic symptom onset

No manual for this!

Rituals / accommodation further reinforce symptoms

Contribute to further impairment / severity
Case report of CBT for rapid onset pediatric OCD of the PANDAS phenotype in a six-year-old boy. (Storch et al., 2004)

- Over a one-week intensive CBT protocol, marked symptom reductions measured by the CY-BOCS were found (Pre-treatment of 34, Post-Treatment of 8); treatment gains were maintained for one-year.

Considerable clinical experience
Participants

Seven children with PANDAS related OCD

- Aged 9-13 years ($M = 11.1$, $SD = 1.4$)
- 4 males, 3 females

Inclusion Criteria:
- primary diagnosis of OCD
- CY-BOCS total score $\geq 16$
- stable on psychotropic medication at least 8 weeks prior to study

Exclusion Criteria:
- psychosis, pervasive developmental disorder, bipolar disorder, or current suicidality
- diagnosis of mental retardation, or any psychiatric disorders or conditions that would limit their ability to understand CBT
## Clinical Presentation

<table>
<thead>
<tr>
<th>Subject</th>
<th>Age/Gender</th>
<th>Primary Obsessions</th>
<th>Primary Compulsions</th>
</tr>
</thead>
</table>
| 1.      | 10-year-old female | Contamination fears  
Aggressive thoughts  
Somatic              | Washing/Cleaning  
Checking  
Ordering/arranging  
Reassurance seeking |
| 2.      | 10-year-old male   | Contamination fears  
Aggressive thoughts  
Sexual thoughts      | Washing/Cleaning  
Repeating  
Counting  
Reassurance seeking  
Washing/Cleaning     |
| 3.      | 12-year-old male   | Contamination fears | Washing/Cleaning                         |
| 4.      | 11-year-old female | Contamination fears  
Aggressive thoughts  
Magical thoughts     | Washing/Cleaning  
Checking  
Ordering/Arranging   |
| 5.      | 13-year-old male   | Contamination fears  
Aggressive thoughts | Washing/Cleaning  
Checking  
Ordering/Arranging   |
| 6.      | 9-year-old male    | Contamination fears  
Somatic fears        | Washing/Cleaning  
Checking  
Ordering/Arranging   |
| 7.      | 11-year-old female | Contamination fears               | Washing/Cleaning  
Checking  
Ordering/arranging   |

Clinical Presentation
Procedure

- Unblinded raters

- Assessments were conducted at four time points: baseline, pre-treatment, approximately four weeks later, post-treatment, and 3-month follow-up

- All patients received 14 90-minute CBT sessions over 3 weeks.
<table>
<thead>
<tr>
<th>Scale</th>
<th>Baseline M (SD)</th>
<th>Pre-TX M (SD)</th>
<th>Post-TX M (SD)</th>
<th>P-value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>CY-BOCS</td>
<td>28.0 (4.6)</td>
<td>31.4 (5.9)</td>
<td>10.0 (6.7)</td>
<td>.018</td>
<td>3.38</td>
</tr>
<tr>
<td>ADIS-P</td>
<td>6.4 (1.1)</td>
<td>6.4 (1.1)</td>
<td>2.4 (2.2)</td>
<td>.018</td>
<td>2.30</td>
</tr>
<tr>
<td>CGI-S</td>
<td>3.7 (0.8)</td>
<td>4.3 (1.0)</td>
<td>1.4 (1.0)</td>
<td>.017</td>
<td>2.90</td>
</tr>
</tbody>
</table>
71% and 50% were diagnosis free at Post-treatment and Follow-up.

86% and 50% were rated as much or very much improved at Post-treatment and Follow-up.
Our findings

- Children showed significantly better ratings at Post-treatment and Follow-up on the CY-BOCS with a very large effect size.
  - On the CY-BOCS, symptom reductions of 68% and 46% were found at Post-treatment and Follow-up, figures that correspond favorably with POTS (2004).

- 71% and 50% of youth were diagnosis free at Post-treatment and Follow-up.

- 86% and 50% were rated as much or very much improved at Post-treatment and Follow-up.
Subjects 1, 4, and 5 experienced partial or full relapses at Follow-up as evidenced by increased ratings on instruments.

- It is notable that Follow-up CY-BOCS scores remained below Pre-treatment levels for two of these youth.
Take home points

- CBT should be a part of the treatment of kids with PANS/PANDAS
  - Despite etiological factors, rituals still reduce anxiety which reinforce further symptoms

- Family involvement is huge – parents as therapist model
  - Empowers families
  - May reduce impact of future bouts
estorch@health.usf.edu