OCD and the Family: Essential Strategies of Effective Treatment

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Family Inclusive Treatments (FIT’s)

“Treating children and teens for OCD (and other anxiety disorders) without the inclusion of parents makes no sense to me.”
--Lynn Lyons, LICSW

“Indeed, higher levels of family accommodation are associated with increased OCD symptoms, increased functional impairment, and poorer treatment outcome in both children and adults (Amir, Freshman, & Foa, 2000).

--Thomson-Hollands, et al., 2014

Tackling OCD in families:

1) Accurate diagnosis
2) Psycho-education…clear, blunt, up front
3) Solid treatment approach (which is a family approach)

Some OCD information…

• About 1/200 children with OCD
• Strong evidence for genetic component, but interaction of genes, biology, environmental and other factors not clearly understood
• Early-onset OCD thought to be more genetic
### Medications and Ped OCD

- SSRI's are the meds of choice.
- Zoloft/Sertraline studied and prescribed most frequently
- Four meds approved for OCD in kids/teens:
  - Anafranil (clomipramine) age 10 and up
  - Prozac (fluoxetine) age 7 and up
  - Luvox (fluvoxamine) age 8 and up
  - Zoloft (sertraline) age 6 and up

### Medications and Ped OCD

- Research supports CBT and E/RP as first line of treatment for all but most severe
- 30-40% decrease in symptoms from meds
- When meds stopped, symptoms return within months
- Gains made with CBT continue after treatment is ended
- Meds can take 8-12 weeks; CBT improvement often seen within a few weeks

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"From direct comparisons of CBT and SRI treatments, we conclude that CBT has the superior efficacy. COMBO versus CBT shows that SRI treatment adds little to concomitant CBT, while COMBO shows favourable outcome versus SRI alone."

Ivarsson, et al., 2015

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### Comorbidity with OCD

- Tic disorder & Tourette's Syndrome
- Attention Deficit/Hyperactivity Disorder
- ASD and Non-Verbal Learning Disability (NVLD)
- Depression
- Other anxiety disorders
Early onset (age 7 or so)

- Symptoms more severe and harder to treat
- More boys than girls

_BUT…_
- A 2015 study showed something else…

“Our hypotheses about a relationship between symptom severity on the one hand and age of symptom onset and gender on the other, were not supported.” (Italics mine)

“However, an unexpectedly strong negative relationship between family functioning and symptom severity emerged. Indeed, family functioning stands apart from the other predictors in the strength of its relationship to symptom severity.” (Italics mine)


The issue of comorbidity

- OCD and ADHD?
  - Stats vary, ranging from 0%-60%
  - Clinically, children often diagnosed with “attention and focus” issues
  - Attention given to executive functioning issues

_BUT…_

- It’s rare to have an adult diagnosed accurately with comorbid OCD and ADHD
- OCD is considered an internalizing d/o
- ADHD is classified as an externalizing d/o
- OCD is on the opposite end of the impulsivity scale, with behavioral inhibition and avoidance prominent

“These profound differences seem to challenge the possibility of a genuine comorbidity between the two conditions, at least on the theoretical level.” (Abramovitch, et al, 2015)
**The Executive Overload Model of OCD**

- Is the child able to perform consistent rituals with the OCD?
- What meds are being prescribed?


**ASD and OCD**

- The presence of cognitive rigidity and ritualized behavior often leads to diagnosis of ASD and OCD.

**BUT…**

- Kids with ASD are NOT disturbed or distressed by the rituals and don’t see them as intrusive!

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**Info about PANS/PANDAS in your handouts at the end**

**Obsessions**
Repetitive, negative thoughts, images or impulses

- **Distress**
Anxiety, fear, disgust, shame

- **Compulsions**
Repetitive thoughts, images or actions

- **Relief**
Distress subsides temporarily
Like All Anxiety Disorders, OCD Demands TWO Things:

- **Certainty:** “I have to know what’s going to happen next…and I want to control it!”
- **Comfort:** “I want to feel safe and comfortable…or else I want out!”

Critical Concepts as we face anxiety…

- **CONTENT** is far less important than **PROCESS**
- We are eliminating **NOTHING**
- We have to teach an **OFFENSIVE** rather than a **DEFENSIVE** position

The question I want you to ask yourself:

Are you as the clinician…

**DOING THE DISORDER?**

Types of Obsessions

- Contamination
- Sexual thoughts
- Fear of doing something awful…something against your values (What if I impulsively act on that thought I had?)
- Doing harm through carelessness or irresponsibility
- Scrupulosity/religious obsessions
- Perfectionism:
  - Exactitude, symmetry, fear of throwing things out b/c might be important, forgetting important information
- Getting a disease (health concerns)
- Lucky numbers, signals, etc.
Types of Compulsions

- Washing
- Checking
- Repeating
- Mental/internal compulsions:
  - Counting
  - Cancelling or undoing
  - Praying
  - Mental reviewing
- Confessing or seeking reassurance

The Content Trap

<table>
<thead>
<tr>
<th>Content (not good)</th>
<th>Process (good!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on &amp; talk about how to fix SPECIFIC obsession</td>
<td>Focus on HOW OCD operates &amp; what it’s up to</td>
</tr>
<tr>
<td>Reassure about that SPECIFIC worry</td>
<td>Cue “OCD-managing” strategies</td>
</tr>
<tr>
<td>Talk rationally and try to problem solve</td>
<td>Be general: “That sounds like your OCD to me…”</td>
</tr>
<tr>
<td>Go over plans &amp; specifics repeatedly</td>
<td>Prompt detachment and movement forward (not elimination!)</td>
</tr>
</tbody>
</table>

Entanglement

The process of “fashioning meanings and warning signals out of passing mental detritus.”

---Seif & Winston (2016)

Immediate Goals:

- Psycho-education
- Simplify and De-Catastrophize
- Positive Expectancy
- Begin shift in both ATTITUDE and FAMILY PATTERNS
FAMILY FRONTLOADING
with
psycho-babble-free
psycho-education

Psycho-education
• With child and parents together (or at times parents alone)
• Poke around in family history a bit
• Blunt, simple, and upfront
• Use the term “OCD” rather than euphemisms
  – “This is the O, this is the C, and the D means it’s not working for you…”

Exercise for Families:
How does OCD get in the way?
• How does OCD control the family?
• Who in the family is in the OCD cult?
• What would you do if OCD wasn't in charge?
• What did you USED to do that OCD no longer allows?
• If you could pick one OCD to get rid of, what would it be?

The importance of working as a family and DECREASING EMOTIONAL INTENSITY

In the context of family involvement in cognitive-behavioral therapy:

Families low in conflict and blaming, and high in cohesion showed an average 93% response rate.

Families high in conflict and blame and low in cohesion showed only a 10% response rate.

(Peris et al., 2012)
We want to demote OCD & worry…

- **CRISIS**
- Expected and predictable
- Part of this family's life
- Even annoying!

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**How OCD Controls Kids**

- **Obsess**
  - Did I/could I do something wrong?"
  - "Something bad could happen"

- **Fear**
  - "I’m scared. I’ve got to get rid of this thought/image/impulse.

- **Ritual**
  - Wash, check, repeat actions, confess, “go over,” etc.

- **Relief**
  - “That worked. I feel better.”

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**So what’s wrong with getting comfortable?**

- Child Has Obsessive Thought
- Feels relief
- Feels Uncomfortable with Uncertainty
- Seeks Immediate Comfort through Avoidance or Compulsion

**Cycle of Obsessions & Compulsions**

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**Step One**

You have a thought, feeling, sensation

**Step Two**

You learn to respond, react differently
Exposure and Response Prevention

E/RP with a dose of \textit{ATTITUDE}

Critical Concepts as we face anxiety…

- CONTENT is far less important than PROCESS
- We are eliminating NOTHING
- We have to teach an OFFENSIVE rather than a DEFENSIVE position

Let's step into doubt and play a different game!

- Child Has Obsessive Thought
- Tolerates Doubt, Moves Back to Activity
- Feels Spike in Anxiety, Uncertainty, and Doubt
- Expects and Allows Thought, Even Invites IT!

Cycle of Obsessions & Compulsions
Expect to worry

• Expect OCD thoughts and doubt to appear in certain situations
• Employ your new information about worry and your OCD thoughts
• Downgrade the OCD from CRISIS to annoying

OF COURSE
you’re going to have these thoughts…

WHY?

1. Because you have OCD and this is what OCD does
2. You’ve been treating the thoughts AS IF they are real
3. So you want to get rid of them because they are bossy and even scary and sometimes weird

Externalizing OCD
The Goal: Create separation between the child and the OCD thoughts

• Name it
• Draw it
• Give it a voice
• Speak about OCD in the third person
Practicing What to Say

- Phrases are practiced and role played
- Write down phrases on index cards
- Stay free of content-based reassurance and rational arguments
- Use the language of allowing rather than eliminating
- Inject a tone of playfulness and energy

Know what you want

Reaching a goal requires finding a “WANT-TO” & then figuring out steps that will get you there

How to get what you want

- Step in to what’s hard & uncomfortable
- Worry and OCD must show up if you are to learn a new way to manage them
- Trying new things or NOT following OCD is a good way to get worry to show up
- Pick goals that you really want to accomplish — you’ll feel more motivated to face your worries
I want ______________________
So I’m willing to________________

Being uncomfortable & uncertain…

• Doubt is the price you pay for moving out of the OCD cult.

• In order to grow, you need to move into new territory and break old patterns.

• Allowing the OCD thoughts and handling uncertainty & discomfort will quiet the power of OCD so you can do what you want to do.

These are messages to try out

• “I’m willing to feel uncomfortable.”

• “I’m willing to let my OCD thoughts come and go.”

• “I’m willing to feel unsure, & to not know what will happen.”

• “I’m willing to grab onto my courage & do it.”
IF I'M UNCOMFORTABLE OR UNSURE OR NERVOUS AS I'M LEARNING SOMETHING NEW OR MOVING THROUGH MY DAY, I'M ON THE RIGHT TRACK...

CRITICAL ATTITUDINAL SHIFT!
Total Cra-Cra versus Tidbit of Truth

E/RP Interventions/Homework:
shake up the existing patterns and create new responses

Homework should:
• Be experiential and active and novel
• Illustrate the larger process(es) that you're teaching... (it's NOT about content!)
• Change/create the emotional tone of therapy (and often the tone of the anxious/depressed family)
• Be the basis of your treatment, not an adjunct to it
Creating an Assignment

• Be collaborative…
  – What OCD pattern would you like to start with?
  – Would you like to a small one or a big one?
• Hierarchies are not needed
• Role play with the OCD

Creating an Assignment

• Predict with parents and child what OCD will do.
  – “What will the OCD say?”
  – “How will the doubt make your body feel?”
  – “What will your parents do if they get sucked back into the cult?”
  – “What will happen if you move on when OCD shows up?”
• Emphasize that we expect and want OCD to show up.

Handling OCD

Do NOT pay attention to the content

Accept obsession when it pops up
  • “It’s fine I just had that thought.”

BE WILLING to make yourself uncertain

BE WILLING to be anxious & stay anxious

Parents, Therapist, and School…
…Everyone on the same page
Problems at School:

- School unaware of diagnosis
- Lack of information/knowledge in general about OCD
- Staff unknowingly reinforces OCD (particularly perfectionism)
- OCD intrusive thoughts treated as dangerous
- Accommodations are avoidance-based and content-based

Traps to watch out for...

- Accommodations with no weaning off plan
- Creating “escapes” that are warm, safe, & cozy… and support avoidance
- Diminishing anxiety by creating certainty (responding to questions, giving information, consistently reassuring)

How do we teach and cue a different response?

- Expectations and normalizing
- Externalization and talking back
- Moving toward rather than backing out
- TRAPS:
  - Accommodation
  - Reassurance
  - Content!
  - Certainty
  - Avoidance

Remember the question I want you to ask yourself?

Are you as the clinician...

**DOING THE DISORDER?**
To make OCD/worry stronger...

- Talk about the content of the obsessions
- Analyze and examine
- Search for and discuss the WHY
- Promote calmness as the prerequisite for moving forward
- Work getting rid of obsessive thoughts

Cognitive techniques that I don't use:

- What's the worst that could happen?
- Let's examine the likelihood of that happening...what are the odds?
- Problem solving around the obsession, also called co-compulsing
- Scheduling or setting aside “worry time” (sometimes also known as “therapy”)

Changing the reaction to the OCD thought....

- **Expect:** When does OCD show up? What does OCD say? What is the consistent theme?
- **Externalize:** Create distance from your OCD thoughts and observe them, but let them be there
- **Experiment:** Take action, shift your attitude, change your reactions...do the OPPOSITE and be on OFFENSE

Information Stuff

- Website: lynnlyonsnh.com and
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- To get my newsletter: Go to FB page and click on EMAIL SIGN UP, or email me and ask.
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**PANDAS**

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

Presence of Group A β-hemolytic streptococcal infection (GABHS) triggers immune system to produce antibodies in blood to fight the infection. The antibodies, rather than attacking the strep, attack healthy cells in basal ganglia, influencing OCD.

**PANDAS**

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

- A variant of rheumatic fever?
- Some genetic predisposition
- Boys 6.2 to 1 girls
- 64% have both OCD & tic disorder
- 40% have ADHD
- 20% have separation anxiety disorder

**Diagnosis**

- Having symptoms of OCD &/or tic disorder
- Onset between ages three & puberty
- Sudden onset
- Symptoms wax & wane in severity
- Positive throat culture for strep (Group B-hemolytic streptococcus) and/or high levels of antistreptococcal antibodies in blood when symptoms are worse

**Treatment**

- Full course of antibiotics whenever episode of strep occurs

**PANS**

(Pediatric Acute-onset Neuropsychiatric Syndrome)

I. Abrupt onset of OCD or severely restricted food intake

II. Presence of at least 2 of the following 7 categories (with similarly severe & acute onset)

1. Anxiety
2. Emotional lability and/or depression
3. Irritability, aggression &/or severely oppositional behaviors
4. Behavioral (developmental) regression
5. Deterioration in school performance
6. Sensory or motor abnormalities
7. Somatic symptoms (i.e. sleep trouble, enuresis, urinary frequency)
PANDAS/PANS
(Pediatric Acute-onset Neuropsychiatric Syndrome)

Sudden, rapid-onset of obsessive-compulsive behavior, as well as possible movement and behavioral abnormalities, including:

- Severe separation anxiety
- Anorexia or disordered eating
- Urinary frequency
- Tics and/or purposeless motor movements
- Acute handwriting difficulty