

# Psychoeducation for Children, Parents, and Family Members about OCD and its Treatment

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THE MATHISON CENTRE  
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# Psychoeducation: Why Is It Important?

1. Engagement of children and parents in treatment
2. Realistic expectations and providing hope
3. Core component of treatment (particularly CBT)

# Objectives

1. Gain knowledge regarding the diagnostic criteria for OCD and be able to describe typical symptoms and course.
2. Appreciate that OCD is a brain-based, highly heritable disorder.
3. Understand treatment options including therapy (exposure and response prevention) and medications.

# The Big Questions

- What Is OCD? (Diagnosis and typical symptoms)
- How Common is OCD? (Epidemiology – Prevalence)
- What Causes OCD? (Etiology and Pathogenesis)
- Does OCD Get Better? (Course, Prognosis)
- How Is OCD Treated?
- Suggested Resources for Youth and Families.

# What is OCD? Diagnosis

# OCD Diagnosis (DSM-5)

## A: Either Obsessions or Compulsions

- Obsessions defined by

- 1) Recurrent, intrusive thoughts, urges or images that are experienced, at some time during the disturbance, as intrusive and unwanted and that cause marked anxiety or distress.
- 2) ...not simply excessive worries about real-life problems
- 3) The person attempts to ignore or suppress [obsessions], or to neutralize them with some other thought or action
- 4) The person recognizes that the [obsessions] are a product of his/her own mind

- Compulsions defined by:

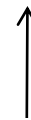
- 1) repetitive behaviours (e.g. hand washing, ordering, checking) or mental acts (e.g. praying, counting, repeating words silently) that the person feels driven to perform in response to an obsessions, or according to rules that must be applied rigidly
- 2) [compulsions] are aimed at preventing or reducing distress or preventing some dreaded event or situation; however [compulsions] are not connected in a realistic way with what they are designed to neutralize or are clearly excessive.

# OCD Diagnosis (continued)

- B. Cause marked distress, are time-consuming (>1 hour/day), or significantly interfere with person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.
- C. If another Axis I disorder is present, the content of obsessions or compulsions is not restricted to it (e.g. preoccupation with food in the presence of eating disorder).
- D. Not due to direct physiological effects of substance (drug of abuse, a medication) or a general medical condition.



# Clinical OCD: Tip of the Iceberg?



Clinical  
OCD  
(2-3%)

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Normal  
population  
variation in  
OC symptoms

# Symptom Dimensions in OCD

OCD has distinct symptom dimensions (Bloch et al., 2008):

- “Symmetry”: Ordering, Repeating, Counting, Checking
- “Forbidden Thoughts”: Aggressive, Sexual, Religious
- “Cleaning”: Contamination + Somatic Obsessions, Cleaning compulsions

# Common Comorbid Conditions

Rates of comorbid disorders high (50-75%):

- ADHD
- Anxiety disorders (e.g. GAD, SAD)
- Tic disorders (early onset, young age, boys)
- Mood disorders (older children/adolescents)
- ODD – irritability

# Obsessive-compulsive and Related Disorders

- OCD
- Hoarding Disorder
- Hair Pulling Disorder
- Body Dysmorphic Disorder
- Skin picking/Excoriation Disorder

# How Common is OCD in Kids?

# Epidemiology – Quick Facts

- 1-2% lifetime prevalence
  - How many kids are in your school?
- Among 10 leading causes of disability according to World Health Organization (Murray and Lopez, 1996)
- Usually begins in childhood or adolescence
  - Median age of onset = 15 (Karno & Golding, 2001)
- Possible bimodal onset
  - Early (mean age 10-11) and adult (mean age 21) onset forms may have distinct features – younger children more likely to be male, comorbid tics, positive family history (AACAP Practice Parameters 2012; Taylor et al., 2011)

# What Causes OCD?

# OCD as a Neurobehavioural Disorder

- Biological but sensitive to the environment (learning)
- Waxes and wanes – either spontaneously or in response to stressors
- Changes in specific brain “circuits”, possibly including altered neurotransmitter signaling
- Altered cognitive processing: e.g. cognitive flexibility, error processing

N.B. IQ is not affected.



# Evolutionary Perspective: Why is OCD so Common?

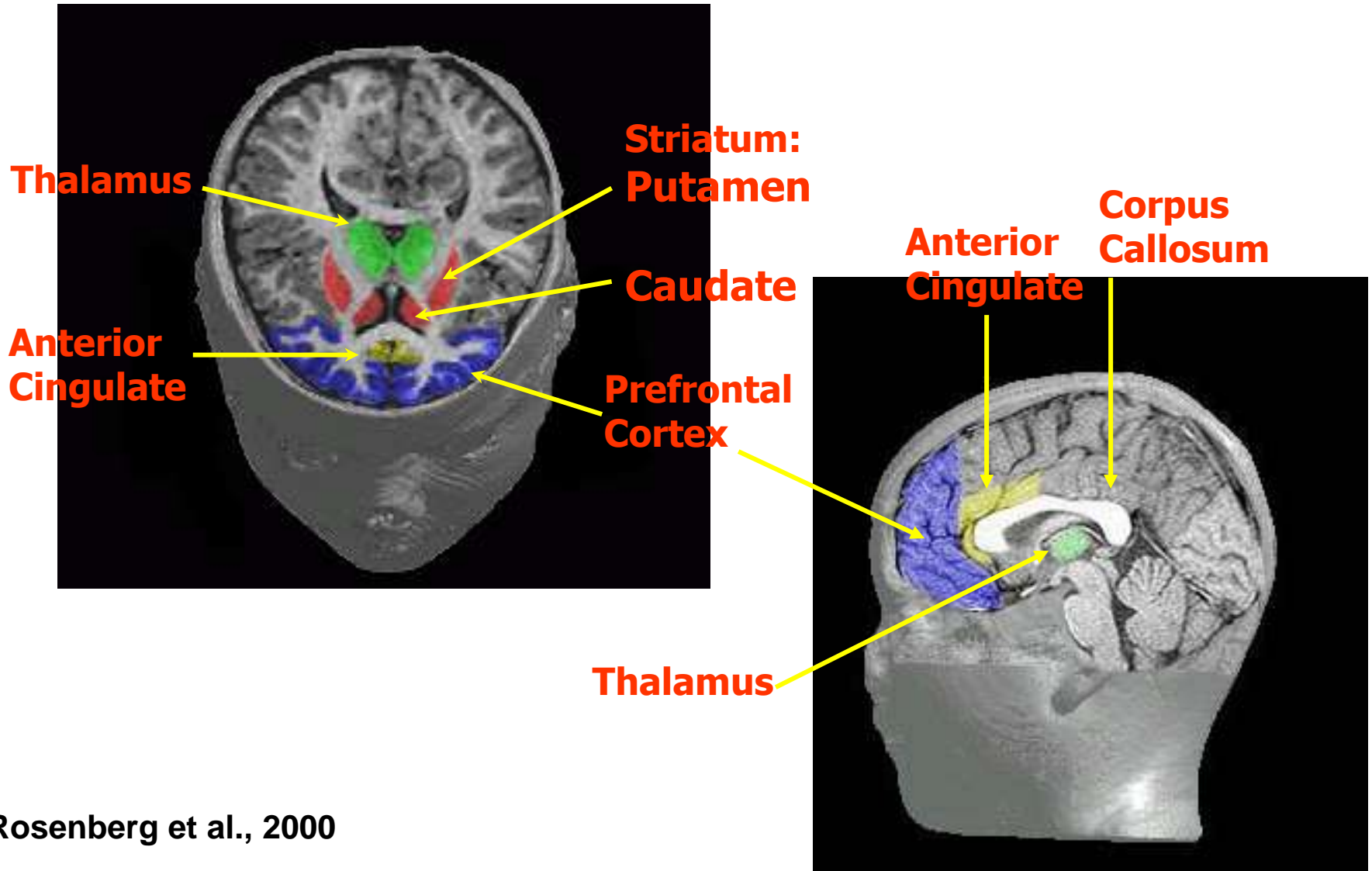
- OCD isn't about "weird" thoughts or habits – lots of OCD symptoms make sense in right context – e.g. previously hand-washing and COVID-19
- Thought patterns and behaviours that are important for survival
- Anxiety and OCD as false "alarm" that is difficult to shut off
- Helps destigmatize the disorder

# OCD: Causes and Mechanisms

- Genetic: Immediate family members of children with OCD have significantly increased risk of having disorder themselves
- Changes in specific brain “circuits”, possibly including altered neurotransmitter signaling
- Altered cognitive processing: e.g. cognitive flexibility, error processing

N.B. IQ is not affected.

# Brain Structures Central to OCD



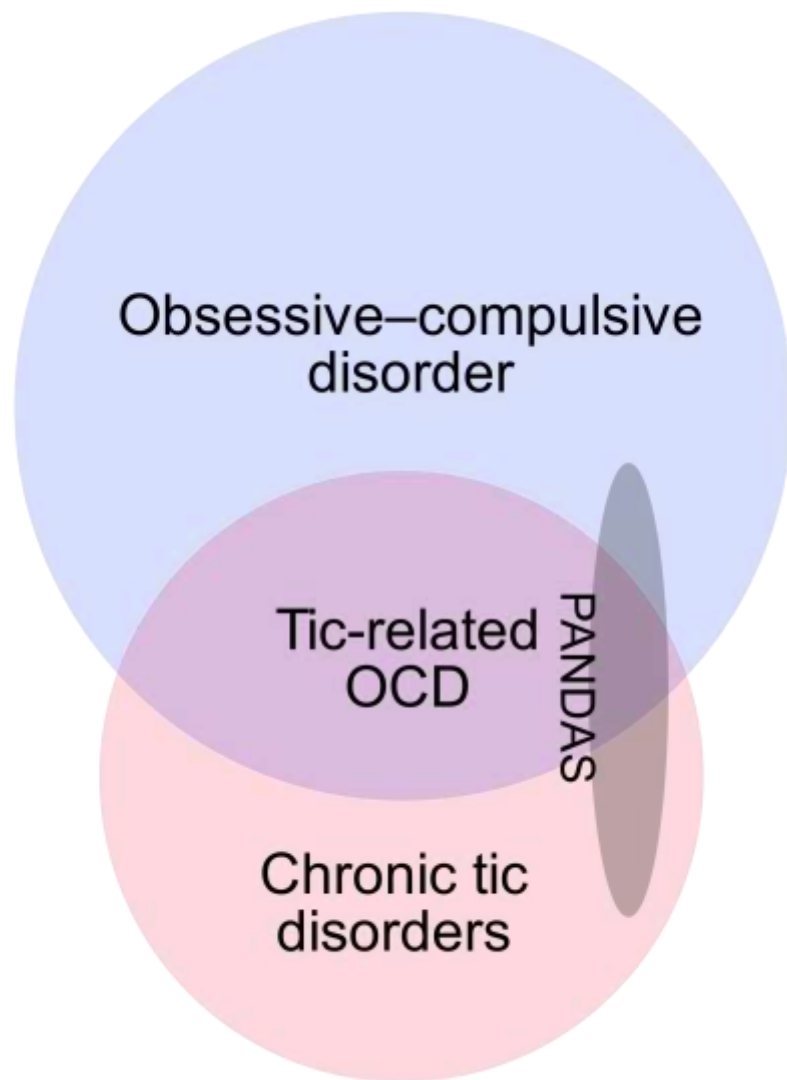
Rosenberg et al., 2000

# Neuropsychological Studies in Childhood OCD

- Response inhibition – evidence for deficit in adults with large effect size (Lipszyc et al), less evidence in children (e.g. Ornstein et al., 2009)
- Cognitive flexibility and reversal learning
- Error processing

# “PANDAS”: Possible Autoimmune Subtype of OCD?

- PANDAS: Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection (Swedo et al., 1998)
- “Epidemiologic evidence and expert clinical experience support the belief that a small subset of children with OCD and TS has onsets and clinical exacerbations caused by Group A B-hemolytic Strep (GABHS) bacteria and basal ganglia” (from AACAP Practice Parameters, 2012).
- Controversy exists as to whether this is autoimmune variant of disorder (and should be treated accordingly) vs. GABHS being one of many non-specific physiological stressors that can trigger symptoms
- Controversy re appropriate treatment as limited evidence from randomized controlled trials, an area of active research.



# Pediatric Acute Onset Neuropsychiatric Syndrome (PANS, Swedo et al., 2012)

1. Unusually abrupt onset of obsessive-compulsive symptoms and/or severe eating restrictions
2. At least 2 co-occurring cognitive, behavioural, or neurological symptoms
3. Symptoms not better explained by known neurological or medical disorder

“PANDAS” is assumed to represent a subset of PANDAS cases with postinfectious cause, PANS a much broader concept which is more “agnostic” with regards to cause.

# Does OCD Get Better?

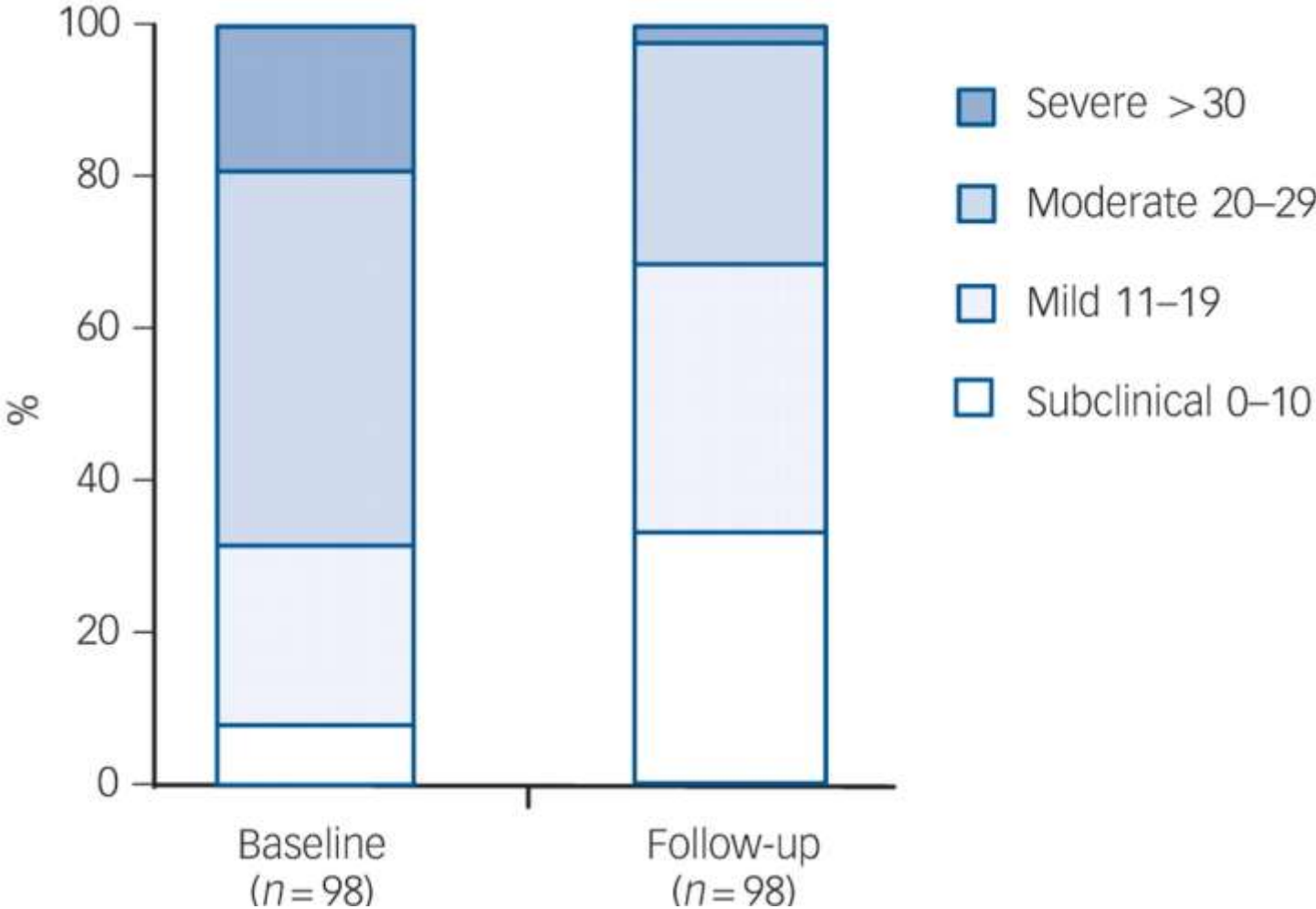
## Course, Prognosis



# OCD: Course of Illness

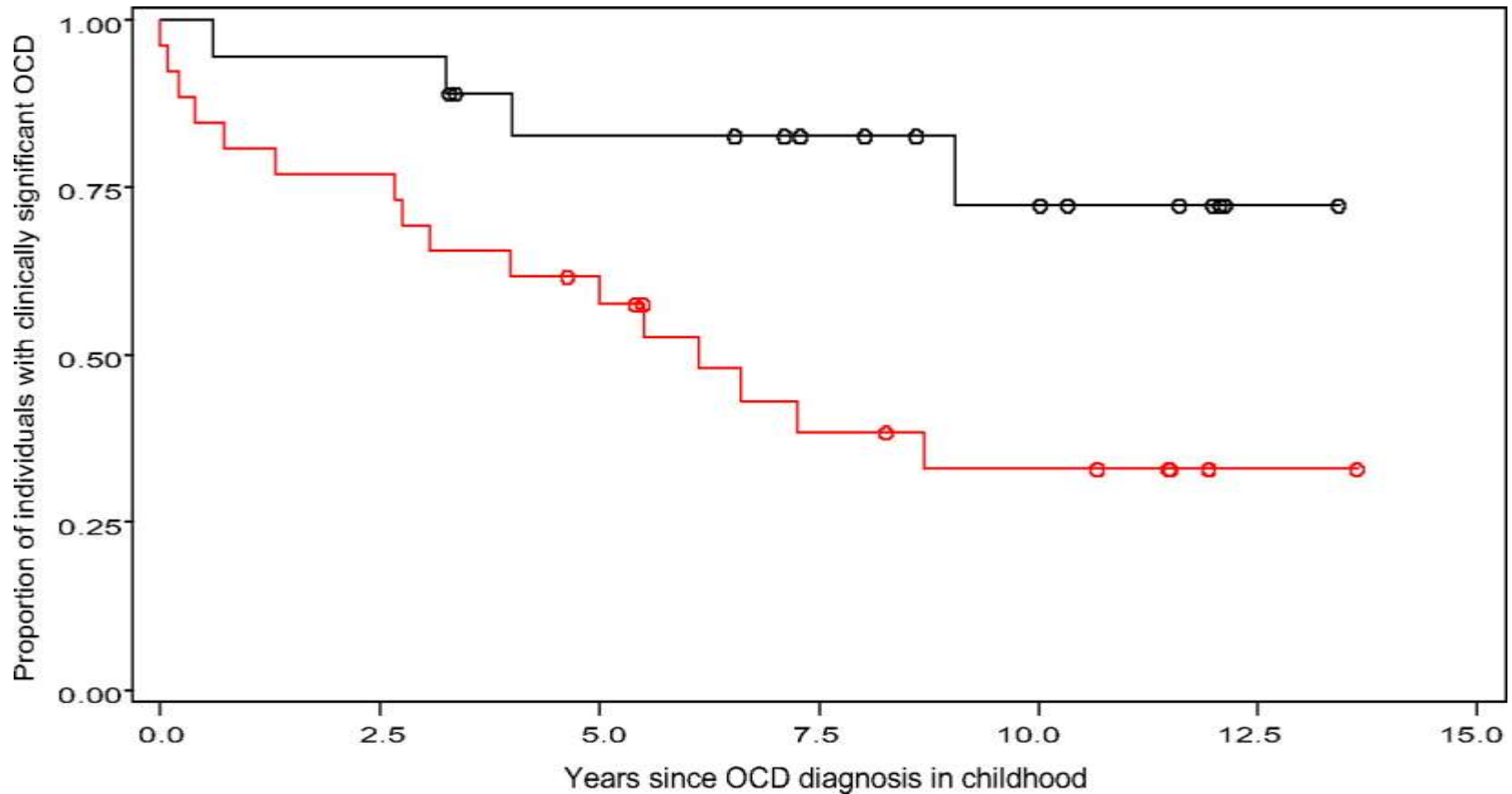
- Long-term outcome studies of pediatric OCD (5 – 9 years):  
Remission: ~40%
  - Predictors of persistence:
    - Increased OCD duration, inpatient status (Stewart et al., 2004)
    - Absence of tics at baseline Tic disorder (Bloch et al., 2009; Micali et al., 2010)
    - Hoarding (Bloch et al., 2009)
    - Early age of onset (
  - Often other disorders are just as common than OCD at follow-up: e.g. Especially Major depression, GAD
- (Stewart et al., 2004; Bloch et al., 2009; Micali et al., 2010)

# Children's Yale–Brown Obsessive Compulsive Scale scores at baseline and follow-up.



Micali N et al. BJP 2010;197:128-134

**Survival curves comparing patients with OCD with and without comorbid CTD (red curve indicates patients with comorbid CTD; black curve, patients without CTD; circles, censored observations).**



**Bloch M H et al. Pediatrics 2009;124:1085-1093**

# How is OCD Treated?

# Childhood Onset OCD: Treatment

- Short-term goal is management, not cure
- First-line treatments:
  - Cognitive-behavioural therapy (Exposure and Response Prevention)
  - Medications: SSRI's
  - Combination may be best (POTS I study)
- Developmental factors must be taken into account
- Consider:
  - Availability & cost of high-quality treatment
  - Personal preference of child/adolescent & parents
  - Severity
  - Comorbidity (e.g. depression)

# 1<sup>st</sup> Line Treatment: Cognitive Behavioural Therapy (CBT)

- First line treatment for mild to moderate OCD, supported by multiple RCTs (e.g.) and Practice Parameters
- Manualized, can be individual or group-based
- Family involvement is key – parents as allies in treatment and reducing **accommodation**
- Core component = Exposure and response prevention

(Barrett et al., 2004; March et al., 2005; Watson & Rees, 2008; AACAP Practice guidelines, 2012)



***Exposure In Vivo***

# OCD Pharmacotherapy

- For moderate-severe OCD, medication is indicated in addition to CBT
- Serotonin Reuptake Inhibitors (SRIs) are first-line medications for OCD & should be used according to AACAP guidelines to monitor response, tolerability and safety
- SRIs - Controlled clinical data in children and adolescents (as low as 6-8 yo) all with positive results:
  - Clomipramine (Leonard et al, 1989)
  - Sertraline (March et al, 1998; POTS study 2004)
  - Fluvoxamine (Riddle et al, 2001)
  - Fluoxetine (Riddle et al., 1992; Geller et al, 2001)
  - Paroxetine (Geller et al, 2004)
  - Citalopram: only an open trial (Thomsen et al, 2001) and a comparison with fluoxetine (Alaghband-Rad & Hakimshooshtary, 2009: CIT=FLX); no placebo-controlled trials



# OCD Pharmacotherapy (cont.)

- Adequate trial duration: 10-12 weeks
- Response rates about 50%; Remission rate 24% (POTS)
  - Therefore families should be informed likely outcome is response rather than remission.
- Meta-analysis of 12 pediatric drug trials (n=1044) indicated no significant differences between SSRI's (Geller et al., 2003)
- Open-label studies up to 1 year indicated continued gains on SSRIs, no additional adverse effects (Cook et al., 2001)

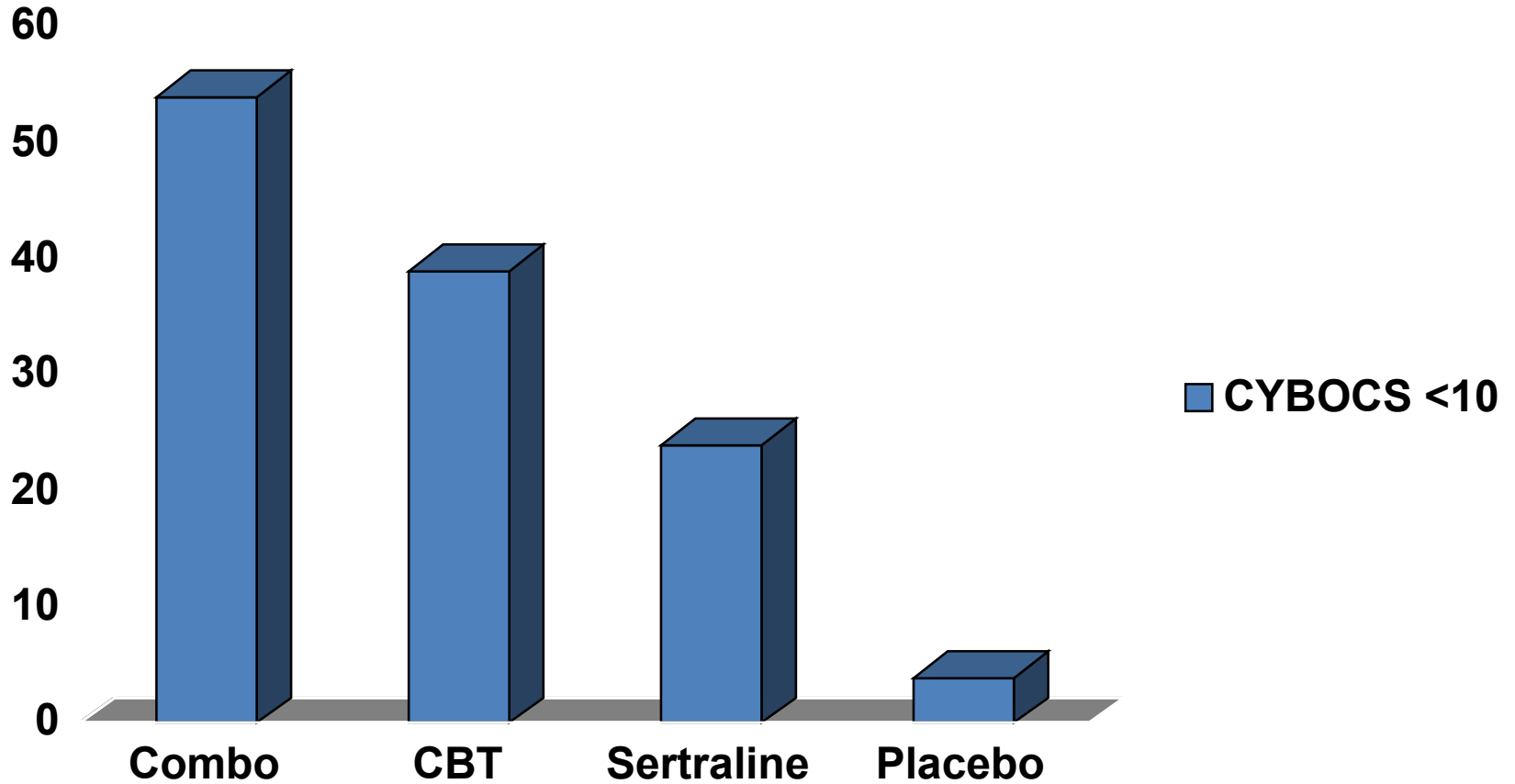
# OCD Pharmacotherapy: Meta-analyses

- The following meta-analyses found that the **effect size (ES)** of SRIs vs. placebo for pediatric OCD is **0.4-0.5 (“medium”)**:
  - Geller et al., 2003: **ES=0.46** (corresponding to a difference of about 4 points out of 40 on the CY-BOCS)
  - Watson & Rees, 2008: **ES=0.48**
  - Ipser et al., 2009: **ES=0.52**
- All 3 meta-analyses found that clomipramine was superior to SSRIs, but Ipser et al., 2009, noted that this finding is based on a single small trial (DeVeugh-Geiss et al., 1992)
- Another meta-analysis found that the **number needed to treat (NNT)** for SRIs vs. placebo was **6** (Bridge et al., 2007)

# Pediatric OCD Treatment Study (“POTS”)

- 112 pediatric OCD patients from 3 centres randomized to Sertraline (up to 200 mg/d), CBT, CBT + sertraline, or pill placebo for 12 weeks
- Manualized CBT - 14 visits over 12 weeks spread across 5 phases: psychoeducation, cognitive training, mapping OCD, Exposure and Response Prevention (ERP), relapse prevention and generalization training
- Response (Change in CY-BOCS score):
  - All treatments better than placebo
  - Combo > Sertraline = CBT > PBO
- Remission rates (CY-BOCS  $\leq 10$ ): Combo best

# Remission Rates: POTS Study



# Predictors and Moderators of Outcome (from POTS)

- March et al. (2007) OCD with tics:
  - CBT or combo work, Sertraline = PBO
  - Limitations: Small N in tic group (17)
- Garcia et al. (2010):
  - Greater improvement across treatment conditions:
    - Decreased severity
    - Decreased functional impairment
    - Greater insight
    - Fewer comorbid externalizing symptoms
    - Lower levels of family accommodation
  - Family history of OCD was associated with >6X decrease in effect size for CBT monotherapy

# Psychoeducation: Presenting Treatment Plan

- Remember 1<sup>st</sup> principles: Engagement, Setting expectations while conveying hope, Treatment “buy-in”
- Build rapport:
  - Relaxed, fun, humor
  - Be genuine, direct, and honest
  - Age-appropriate language – e.g. “Sticky thoughts”
- Talk about building skills to battle OCD
- Treatment provider(s), family and patient as “team”
- Normalize and externalize OCD (may give it name)

# Psychoeducation: Presenting Treatment Plan

- Confirm diagnosis
- Provide answers to most common questions:
  - It's common, you are not alone
  - It's a brain-based, heritable disorder but can also be sensitive to environment
  - It gets better but the short-term goal is management, not cure
- Treatment Plan
- Any questions? Suggested Resources for Youth and Families.

# Recommended Resources

- International OCD Foundation (IOCDF)

[www.iocdf.org](http://www.iocdf.org)

- Anxiety Canada

[www.anxietycanada.com](http://www.anxietycanada.com)

- Tourette OCD Alberta Network!