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OVERVIEW

The ABCs of OCD

REVIEW

Confronting compulsions and obsessions

Treating childhood obsessive-compulsive disorder



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ABOUT THE CHILDREN'S HEALTH POLICY CENTRE

We are an interdisciplinary research group in the Faculty of Health Sciences at Simon Fraser University. We aim to improve children's social and emotional health and reduce health disparities starting in childhood. To learn more about our work, please see childhealthpolicy.ca.

ABOUT THE QUARTERLY

In the *Quarterly*, we present summaries of the best available research evidence on children's mental health topics, using systematic review and synthesis methods adapted from the *Cochrane Collaboration* and *Evidence-Based Mental Health*. The BC Ministry of Children and Family Development funds the *Quarterly*.

QUARTERLY TEAM

Scientific Writer Christine Schwartz, PhD, RPsych

Scientific Editor Charlotte Waddell, MSc, MD, CCFP, FRCPC

> Research Coordinator Jen Barican, BA

Research Analyst Stephanie Dickson, BHK, MPH

Research Assistant Larry Nightingale, LibTech

Production Editor Daphne Gray-Grant, BA (Hon)

> Copy Editor Naomi Pauls, MPub



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THIS ISSUE



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At any given time, some 21,500 children in Canada experience obsessive-compulsive disorder. We describe how this disorder affects children and how adults can support them.



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High-quality studies have identified cognitivebehavioural therapy and selected medications as effective treatments for OCD in children. We compare and contrast the risks and benefits of each approach.



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A reader notes that when parents seek treatment, all their mental health concerns — including

substance misuse — should be addressed. We outline one approach for achieving this.

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NEXT ISSUE Kinship foster care

When parents cannot care for their children, other family members may be able to step in. We examine the experiences and outcomes for children in kinship foster care.

How to Cite the Quarterly

We encourage you to share the *Quarterly* with others and we welcome its use as a reference (for example, in preparing educational materials for parents or community groups). Please cite this issue as follows:

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The ABCs of OCD

Understanding that it is obsessive-compulsive disorder has been helpful for him and us. It's not bad behaviour or silly. It's a condition that's understood and needs treatment.

— Father of a child with OCD¹

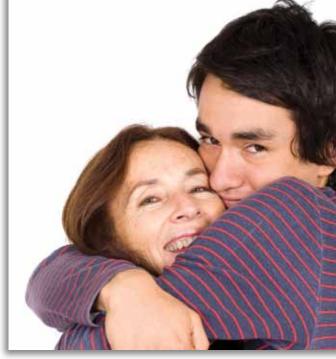
any children occasionally have unwanted thoughts that they find difficult to stop. But for some children, unwanted thoughts become intrusive — occurring frequently and causing distress. These unwanted and intrusive thoughts, or *obsessions*, are often accompanied by *compulsions*. These are repetitive behaviours or mental acts that a child feels driven to perform to reduce their distress, even though the acts are excessive.² When a child experiences either obsessions or compulsions that are time-consuming or that cause significant impairment, a diagnosis of obsessive-compulsive disorder (OCD) may be warranted.²

For children with OCD, obsessions often involve fear of harm (e.g., to oneself or others) or fear of contamination (e.g., excessive concerns with dirt, germs and illness). Across four recent studies, 38% to 66% of young people with OCD had fear of harm, while 39% to 64% had fear of contamination. ³⁻⁶

Children with OCD also experience certain types of compulsions more frequently, particularly checking and cleaning. For example, a child with a checking compulsion may frequently seek out his mother to ensure that she has not been hurt, or repeatedly check that doors are locked. Across the previously noted studies, 49% to 64% of young people with OCD experienced checking, while 36% to 53% cleaned compulsively. Some compulsions, such as cleaning, may be relatively easy to recognize. But others are less obvious. For example, compulsions involving a child repeatedly counting or silently reciting certain words may be more difficult to detect.⁷

How many children are affected by OCD?

Based on data from several high-quality epidemiological surveys, approximately 0.4% of four- to 17-year-olds meet diagnostic criteria for OCD. $^{8-10}$ This means that as many as 2,700 children in BC — or 21,500 in Canada — may be affected at any given time.



Approximately 0.4% of four- to 17-year-olds meet diagnostic criteria for OCD.

If, after careful assessment, a child is diagnosed with OCD, effective treatments should be provided as soon as possible.

When is a diagnosis warranted?

ost practitioners use criteria set out in the *Diagnostic and Statistical Manual of Mental Disorders* when determining whether a child has OCD.² These criteria include a child having either obsessions or compulsions.

Obsessions are recurrent and persistent thoughts, urges or images that are intrusive and cause the child significant distress. Children usually respond to their obsessions by making efforts to stop, ignore or counteract them.

Compulsions are repetitive behaviours or mental acts that children feel driven to perform in response to an obsession or to rules that they feel compelled to apply precisely. Children engage in compulsions to reduce their distress or to prevent a dreaded event from occurring. However, the behaviours are excessive or unrealistic. For example, a girl touches a photo of her mother 10 times, believing that doing so will keep her mother safe from harm.

Obsessions and compulsions must also be time-consuming (i.e., taking more than an hour a day) or cause significant distress or impairment (e.g., interfering with school). Finally, the symptoms must not be due to a substance or other disorder.

What causes OCD?

Biological factors likely play an important role in the development of OCD. In fact, researchers have started to identify specific genes and chromosomes associated with increased vulnerability. Some studies have also found that a small subset of children develop the disorder following streptococcal infections. Still, given the complexity of causal pathways for mental disorders, more research is needed to help refine intervention efforts, especially for OCD given that no effective prevention programs exist.

How adults can help

Adults can do several things when they believe a child may have OCD. The first step is to obtain a comprehensive assessment by a qualified mental health practitioner, such as a child and adolescent psychiatrist or psychologist. The assessment should include a detailed review of the child's developmental history, symptoms and impairment; it might also include measures specifically designed for diagnosing childhood OCD, such as the Children's Yale-Brown Obsessive Compulsive Scale.

A comprehensive assessment is crucial to help understand the child's symptoms. For example, a toddler demanding rigid bedtime routines might simply be experiencing a typical development phase rather than a compulsion. As well, repetitive behaviours common in children with OCD must be distinguished from those occurring in children with autism spectrum disorder.

If, after careful assessment, a child is diagnosed with OCD, effective treatments should be provided as soon as possible. (Effective OCD treatments are described in this issue's Review article.)

Parents are paramount

When a young person has OCD, parents will often take extraordinary steps to try to reduce their child's distress. These well-intentioned efforts may include enabling their child to avoid feared situations, participating in compulsive behaviours, and modifying family routines and their own work schedules to accommodate symptoms.¹³ One study found that roughly half of parents participated in their child's rituals *every day*.¹³

Yet despite parents' best intentions, accommodating a child's OCD symptoms may actually increase the obsessions and compulsions over time.

Instead, children (and parents) benefit more when parents are taught effective strategies for addressing OCD. For example, in cognitive-behavioural therapy, parents are taught — and strongly supported — to successfully disengage from accommodating their child's behaviours, with the result that OCD symptoms lessen.

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Some parents — particularly those with OCD themselves — may need extra support. These parents have been found to be *more* likely to modify family routines as a consequence of their child's OCD *and* to experience greater distress when they do.¹³ As well, children whose parents also have OCD frequently struggle more when their parents try to disengage from accommodating their children's symptoms.¹³ Therefore, these parents often need additional assistance, as well as referrals to receive their own treatment.

The bottom line

Children with undetected or untreated OCD experience considerable distress and impairment. Many struggle not only with their symptoms, but also with shame and embarrassment *because* of their symptoms. Many report having a lower quality of life, including reduced emotional and social well-being and poorer school functioning. Above all, these children should not receive negative messages or negative consequences for their OCD symptoms. Instead, they need to receive ample supports and effective treatments. The Review article that follows describes several effective approaches for treating OCD — and for preventing unnecessary distress, impairment and stigma.

Where BC children and parents can find support

Support is available for young people with OCD living in BC. Children, teens and their families can access assessment and treatment services at their local Ministry for Children and Family Development Child and Youth Mental Health office or from their family physician. The Obsessive-Compulsive Disorder Clinic at BC Children's Hospital can also provide specialized consultation to children who have not responded to a prior course of treatment. To be eligible for this service, young people must be referred by their physician. Parent or caregiver involvement is also required. This clinic also provides education to families, schools, practitioners and public health agencies.

When a young person has OCD, parents will often take extraordinary steps to try to reduce their child's distress.

Confronting compulsions and obsessions

n an <u>earlier issue</u> of the *Quarterly*, we summarized the best available research evidence on treating childhood obsessive-compulsive disorder (OCD). Outcomes from four randomized controlled trials (RCTs), published between 1998 and 2004, led us to conclude that cognitive-behavioural therapy (CBT) and sertraline, a selective serotonin reuptake inhibitor (SSRI), were effective treatments for OCD.

Since then, several new RCTs have been conducted — making it possible to compare more treatments. We therefore used our usual <u>methods</u> to conduct a comprehensive search for systematic reviews comparing OCD treatments. Of three

reviews meeting our criteria, we selected Watson and Rees's because it included more RCTs and more types of treatment.¹⁶

To be included in Watson and Rees's review, RCTs had to meet several standard quality criteria. For example, participating children had to have an OCD diagnosis and be under age 19. As well, treatments had to be compared to either placebo or waitlist controls. Of 13 RCTs meeting these criteria, four examined CBT — using both individual and group formats, which included family involvement. The other 10 RCTs examined medications, including four SSRIs (fluoxetine, fluvoxamine, paroxetine and sertraline) and one older antidepressant (clomipramine). (The total number of treatment conditions exceeds the number of RCTs because one RCT assessed both sertraline and CBT. Also, one RCT examined both group and individual delivery of family CBT.) Treatments were provided to children for between five and 16 weeks.

Among the 1,149 children participating in the 13 RCTs, average ages ranged from 11 to 15 years, with boys and girls participating nearly equally. Australian, British and Canadian children each participated in one RCT. Children in all the other RCTs were American.

What's involved in CBT for OCD?

While treatment techniques varied slightly, all four CBT studies nevertheless followed core CBT principles. First, all the studies began with practitioners presenting children and parents with *educational information* about OCD and explaining what was involved in treatment. ^{14, 17–19} As a part of this process, children were encouraged to give the disorder a "nasty nickname" — to help them "boss back" their symptoms and to help ensure they did not feel blamed for their



Practitioners taught children techniques to address physical and cognitive OCD symptoms.

Parents were often trained as "coaches" to support children. OCD.²⁰ Children also identified their specific obsessions, compulsions, triggers and avoidance behaviours.^{14, 17–19}

Next, practitioners taught children techniques to address physical and cognitive OCD symptoms. Children learned *anxiety management strategies*, such as relaxation and breathing techniques.^{14, 19} They also learned *cognitive strategies*, such as challenging their own beliefs about the likelihood of feared outcomes coming true.²⁰ For example, a child who worried that his mother would become sick if he did not repeatedly pray for her would be taught to critically examine the chances of her actually becoming ill, and how he could cope if she did.

In all the studies, children then engaged in the crux of the treatment: *exposure* and response prevention. ^{14, 17–19} This involved helping children confront their obsessions while resisting the urge to engage in compulsions. ¹⁷ For example, a child who feared germs would touch "germy" items then refrain from washing for a defined period of time. ¹¹ Exposure and response prevention was practised during sessions and as homework. Parents were often trained as "coaches" to support children during these exercises. ²¹

Notably, all four of the studies involved parents. In one, parents simply received educational information about OCD and the CBT treatment model.¹⁷ In two studies, parents participated in three sessions with their children.^{18, 19} The remaining study provided family CBT, which involved parents and siblings receiving 16 educational and skill-building sessions (which were held separately from the child sessions).¹⁴

Studies used medication judiciously

The 10 RCTs that included medications typically took a cautious approach to maximizing benefits while minimizing risks. This often involved adhering to strict dosage guidelines to reduce the likelihood of adverse events. For example, in an RCT assessing sertraline, children were seen almost weekly for medication adjustments, and during these visits, any child experiencing an adverse event either had their dose reduced or had their dose increase delayed. As well, in an RCT assessing paroxetine, medication increases were limited in both frequency (no more than once a week) and amount (no more than 50 mg per day).

How well do the treatments work?

To determine effectiveness for both CBT and medications, the review authors calculated pooled effect sizes using pre- and post-treatment scores from the main OCD outcome measure for each intervention. They calculated effect sizes using Cohen's d. Although interpretation standards vary, an effect size of less than 0.4 is typically considered small, 0.4 to 0.7 moderate, and greater than 0.7 large.²⁵

Beyond just indicating *whether* a treatment worked or not, effect size indicates *how well* it worked. For example, a large effect size might mean that after

Treatment with a family focus

hen a child has OCD, the entire family is affected.¹¹ Family members feel considerable distress themselves; they also frequently try to reduce their child's (or sibling's) discomfort by accommodating or enabling OCD symptoms.^{13, 14} Consequently, most versions of CBT for childhood OCD involve family members, at least to some degree.^{14, 17–19, 23, 24}

In fact, of all the studies we reviewed, the most successful one provided family CBT.¹⁴ In this RCT, parents and siblings (between ages seven and 17) participated in 16 sessions, delivered by the child's practitioner. First, practitioners provided educational information about OCD. Then parents and siblings were taught problem-solving skills and strategies to reduce their accommodating behaviours. Next, family members were trained to provide support during homebased exposure and response prevention exercises.

In addition to children with OCD significantly improving as a result of family CBT, both parents and siblings described achieving substantial gains and reported high satisfaction with the treatment. 14 These very positive outcomes highlight the value of making treatments family-focused.

treatment a child stopped engaging in compulsions and rarely had obsessions, while a small effect size might mean that a child still experienced symptoms, albeit less often.

Children receiving either CBT or medication had significantly fewer OCD symptoms than children in the control groups at post-test. And children receiving CBT made particularly substantial gains, as indicated by the very large pooled effect size (1.5) across the four CBT studies. Among these studies, family CBT produced extraordinarily large effect sizes (2.4 to 2.5).

The medications were also generally effective, but their medium pooled effect size (0.5) was less robust than CBT's (1.5). When assessed individually, three of the SSRIs (fluoxetine, sertraline and paroxetine) produced a medium effect size, and one produced a small effect size (fluvoxamine). The one older antidepressant (clomipramine) produced a large effect size. Please see Table 1 below.

Table 1: Obsessive-Compulsive Disorder Treatment Effects		
Treatment	Number of Randomized Controlled Trials*	Pooled Effect Size (Cohen's d)
Cognitive-Behavioural Therapy	4	1.5 — large
Medication (brand name)	10	0.5 — medium
Fluoxetine (e.g., Prozac)	3	0.5 — medium
Sertraline (e.g., Zoloft)	2	0.5 — medium
Paroxetine (e.g., Paxil)	2	0.4 — medium
Fluvoxamine (e.g., Luvox)	1	0.3 — small
Clomipramine	2	0.9 — large

Exceeds total number of randomized controlled trials, because one evaluated both sertraline and cognitive-behavioural therapy.

Building on previous studies

Because Watson and Rees's review was published in 2008, the authors only included RCTs published until January 2007. Consequently, we conducted our own search for RCTs published after that to identify newer studies. We found three additional RCTs that met Watson and Rees's original inclusion criteria. ^{23, 24, 26} The children participating in these three RCTs were similar to those in the systematic review regarding age, gender and countries of origin (United States and United Kingdom).

All three of these newer studies assessed CBT only. However, two included somewhat novel approaches. One compared the efficacy of brief (five-session) CBT with the full-length (12-session) version. And another examined the efficacy of family CBT delivered online by a practitioner counselling by webcam rather than in person.

Increasing the power in numbers

he Quarterly often features systematic reviews - in keeping with our goal to provide the best available research evidence on children's mental health topics. The reviews we highlight typically summarize results from many different studies using a statistical technique known as a meta-analysis. Because they combine information from a number of relevant studies, meta-analyses have a distinct advantage over individual studies: they provide a more precise estimate of treatment effectiveness.25 As well, meta-analyses increase the likelihood of correctly identifying effective treatments. This is because many individual studies include too few participants to be able to detect small but significant treatment effects. Meta-analyses overcome this problem by combining studies, which in turn increases their ability (and power) to identify treatments that truly work well.25

Children receiving
CBT made particularly
substantial gains.

Across all three RCTs, children significantly benefited from CBT. And consistent with the findings from Watson and Rees's review, CBT produced large treatment effects. Specifically, individual CBT produced large effect sizes (ranging from 1.1 to 2.2) whether it was delivered in five, 10 or 12 sessions.^{23, 26} Children participating in family CBT delivered online using webcams experienced similarly large treatment effects (1.4).²⁴

Do CBT's benefits persist?

Preliminary evidence suggests that unlike medications, CBT's effects may persist after treatment ends. Specifically, one of the RCTs identified in Watson and Rees's review found that 65% of children who received individual CBT and 87% who received group CBT continued to be diagnosis-free at six-month follow-up. However, because the control group ceased to exist — as children in this group received treatment by final follow-up — this finding should be considered preliminary. However, because the control group ceased to exist — as children in this group received treatment by final follow-up — this finding should be considered preliminary.

OCD treatments work well for children

Two effective treatments exist for children with OCD: CBT and medications. Of these, CBT is clearly the first choice, based on larger treatment effects across multiple RCTs — without any obvious negative effects.

Beyond corroborating CBT's effectiveness, our review also shows that CBT can be successful in diverse populations of children. Specifically, CBT for OCD can be delivered to boys and girls ranging from seven to 18 years — from a wide variety of ethnic backgrounds. ^{17, 19, 23, 24} Children with complex mental health concerns can also be successfully treated with CBT. For example, 48% to 97% of the children in the RCTs we reviewed met diagnostic criteria for at least one other mental disorder in addition to OCD, and yet responded well to CBT. ^{14, 17, 19, 23, 24, 26}

These findings also demonstrate that CBT can be delivered in a variety of formats — individually, in groups, and with families. ^{14, 17–19, 23, 24, 26} CBT is even effective when it's delivered online via webcam, which may be particularly useful for children in more remote communities. ²⁴

Still, not every child fully responds to CBT. For such children, medication may play an important role. Among the medications with evidence of effectiveness, clomipramine had the strongest effect size. However, this medication also has a more challenging side-effect profile than the four SSRIs found to be effective (fluoxetine, sertraline, paroxetine and fluvoxamine). Specifically, in the two RCTs evaluating clomipramine, rare but serious adverse events included movement disorders, seizures, heart palpitations, and abnormal liver function.^{27, 28} Clomipramine is therefore not recommended as a first choice of medication when CBT has not worked.^{11, 16}

Asking more than just "How well does it work?"

hen we evaluate any intervention, We carefully analyze and report information on its effectiveness. But we don't stop there. We also try to provide a summary of side effects. Our efforts to do so for OCD medications, however, were hampered by limited data provided in many studies. Issues included researchers failing to systematically assess side effects,21 measuring side effects only once rather than repeatedly,28 and reporting only selected side effects.^{5, 19, 21, 22, 27, 29} An evaluation of paroxetine stood out for its failure to even mention side effects in its published report.30

Still, some researchers took a diligent approach to measuring and reporting side effects. For example, one fluoxetine evaluation assessed side effects at least every two weeks and reported *all* side effects, carefully noting which occurred significantly more frequently in children receiving fluoxetine compared to placebo.³¹

In evaluating whether any given medication is the best choice for a particular child, information about side effects is critical. Thus, researchers need to systematically measure and report side effects so practitioners, parents and young people can make well-informed treatment decisions. Regulators also need to carefully monitor side effects as part of their role in protecting the public, especially children.

Instead, according to our review, fluoxetine and sertraline stood out among the SSRIs. Both produced medium treatment effects (0.5) and both had manageable side-effect profiles. Nevertheless, careful monitoring for benefits and side effects is essential when any child is being treated with any medication.

Ensuring children receive effective treatments

Our review offers good news for every child with OCD and their families. With effective treatments, namely CBT (including the core component of <u>exposure and response prevention</u>) and SSRIs (such as fluoxetine and sertraline), the symptoms and distress experienced as a result of this disorder can be greatly diminished.

Yet CBT has compelling advantages compared with SSRIs. It is much more effective, according to the effect sizes that we uncovered. As well, its beneficial effects may be sustained after treatment ends. And there are no known side effects or adverse events associated with CBT.

CBT is also very flexible. It can be delivered in groups and in brief formats (e.g., five sessions). It can also be effectively delivered using novel modalities, such as live webcams, potentially reaching many more children (including those in underserved communities).

Still, more practitioner training is likely needed. For example, a recent survey of clinicians found that only one-third "regularly" used exposure and response prevention when treating children with OCD, despite it being a core component of treating this disorder. This finding suggests that while universities should be offering CBT training and supervision as part of their core curricula for people who plan to work in children's mental health, not all practitioners have had such learning opportunities. For those who have not, CBT training can be taken as part of continuing education.

The upshot is that all children with OCD — and their families — need to be offered CBT. And, if they are not offered CBT, families should specifically request this form of treatment. Then SSRIs (such as fluoxetine or sertraline) should be considered for children with OCD if CBT has not been successful.

Helping practitioners help children

CD in Children and Adolescents: A Cognitive-Behavioral Treatment Manual is an excellent resource. This well-regarded text by March and Mulle (1998) was specifically written for those treating young people with OCD. 19, 21 It was also the basis for the treatment protocols used in two of the RCTs featured in our review. As well as providing session-by-session plans with helpful handouts, it contains useful assessment tools and lists of additional resources for both practitioners and families.

The upshot is that all children with OCD — and their families — need to be offered CBT.

When substance misuse is not the only concern

To the Editors:

As noted in your <u>previous issue</u>, many parents with substance use disorders have additional mental health concerns. Given this, what steps can practitioners take to ensure that other mental health issues are identified and addressed along with substance use concerns?

Yasmin Jetha Victoria, BC

The overlap between substance misuse and other mental disorders is well documented. For example, a large, representative survey of Canadians found that those with substance use disorders were two to three times more likely to have an additional mental disorder.³² Given this, it is crucial that *all* mental health concerns are addressed when parents seek help.

As a starting point, practitioners always need to ask about substance misuse *and* other mental health problems, such as anxiety and depression. Practitioners need to take this approach regardless of the setting — whether primary care or specialized mental health clinics or substance treatment centres.

Then if a parent is experiencing *both* substance misuse *and* other mental health issues, the research suggests that they will benefit more when practitioners use an integrated approach.³³ This involves providing effective treatments — such as motivational interviewing and cognitive-behavioural therapy — in a coordinated rather than piecemeal way.³³ It also involves the same practitioner or team providing treatment so parents do not have to travel to separate clinics and see multiple practitioners.³³ Notably, many programs using an integrated approach provide more comprehensive forms of assistance, such as family interventions and vocational and housing services, to address broader concerns facing many parents.³³

Parents with co-occurring disorders often need considerable support — in their own recovery and in their parenting. And given that adults with co-occurring disorders are more likely to seek services than those with just one disorder, providers need to be ready to deliver integrated and comprehensive services for children to truly benefit.³⁴



Practitioners always need to ask about substance misuse and other mental health problems.

Contact Us

We hope you enjoy this issue.
We welcome your letters and suggestions for future topics. Please email them to chpc_quarterly@sfu.ca
or write to
Children's Health Policy Centre
Attn: Jen Barican
Faculty of Health Sciences
Simon Fraser University
Room 2435, 515 West Hastings St.
Vancouver, British Columbia
V6B 5K3

o identify high-quality research evidence on the effectiveness of interventions aimed at helping children with obsessive-compulsive disorder (OCD), we conducted a comprehensive search — using methods adapted from the *Cochrane Collaboration* and *Evidence-Based Mental Health* and applying the following search strategy:

Table 2: Search Strategy	
Sources	Campbell Collaboration Library, Cochrane, Medline and PsycINFO
Search Terms	Obsessive-compulsive disorder or OCD and intervention, prevention or treatment
Limits	 Peer-reviewed articles published in English between 2003 and 2013 Child participants aged 18 years or younger Systematic review or meta-analysis methods used

Reference lists of relevant systematic reviews were then hand-searched to identify additional reviews. Using this approach, we identified nine systematic reviews. Two team members then assessed each review, finding three that met all our inclusion criteria, as detailed in Table 3.

Table 3: Inclusion Criteria for Systematic Reviews

Systematic Reviews

- · Methods clearly described, including database sources and inclusion criteria
- Original studies limited to randomized controlled trials (RCTs)
- · Magnitude of effects reported
- · Test of homogeneity used
- · Publication bias assessed
- Included at least two RCTs meeting criteria listed below

Original Studies

- · Interventions aimed at children with OCD
- Clear descriptions of participant characteristics, settings and interventions
- Random assignment to intervention and placebo or waitlist control groups at study outset
- Attrition rates below 20% at post-test or use of intention-to-treat analysis
- Outcomes assessed using two or more informant sources (children, parents, others)
- · Reliability and validity of all primary outcome measures documented
- Levels of statistical significance reported for all primary outcome measures

Of the three reviews, we selected Watson and Rees¹⁶ because it included more RCTs and more treatments. To capture RCTs published after this systematic review was completed, we conducted our own searches using the same search terms. We applied criteria for assessing original studies as detailed in Table 3. This new search yielded three RCTs that met Watson and Rees's inclusion criteria. These new studies were reported in our findings.

For more information on our research methods, please contact

Jen Barican
chpc_quarterly@sfu.ca
Children's Health Policy Centre
Faculty of Health Sciences
Simon Fraser University
Room 2435, 515 West Hastings St.
Vancouver, British Columbia
V6B 5K3

BC government staff can access original articles from BC's Health and Human Services Library.

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