### CHILDREN'S MENTAL HEALTH POLICY RESEARCH PROGRAM

UNIVERSITY OF BRITISH COLUMBIA

# Preventing and Treating Obsessive-Compulsive Disorders in Children and Youth

A Research Report Prepared for the British Columbia Ministry of Children and Family Development

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### PREFACE

This report is one in a series of research reports being prepared by the Children's Mental Health Policy Research Program at the University of British Columbia at the request of British Columbia's (BC's) Ministry of Children and Family Development (MCFD). At any given time, over one in seven or 140,000 children in BC experience mental disorders serious enough to impair their development and functioning at home, at school and in the community.<sup>1</sup> To support MCFD's goal to improve children's mental health in BC, in 2002-2003 we produced four reports: on population health and clinical service considerations;<sup>2</sup> on practice parameters for treating attention-deficit/hyperactivity disorder, conduct disorder, depression, obsessive-compulsive disorder and schizophrenia;<sup>3</sup> on child psychiatric epidemiology;<sup>1</sup> and on performance monitoring.<sup>4</sup> In 2003, MCFD announced a new *Child and Youth Mental Health Plan (the Plan)*<sup>5</sup> to better address the needs of children and families in BC.

The research reports prepared by the Children's Mental Health Policy Research Program will support MCFD's *Plan* by identifying the most effective prevention and treatment approaches for a variety of children's mental health problems. This report focuses on treating obsessive-compulsive disorder. Other reports have focused on conduct disorder,<sup>6</sup> anxiety disorders,<sup>7</sup> depression,<sup>8</sup> implementing evidence-based practice,<sup>9</sup> First Nations children,<sup>10,11</sup> early psychosis<sup>12</sup> and suicide.<sup>13</sup>

Our reports are intended to be a resource for policy-makers, practitioners, researchers, families, teachers and community members working with children in BC. We recognize that research evidence is only one component of good policy and practice. This report addresses only the content, or the specific factors, in treating obsessive-compulsive disorder in children. Applying this content in policy and practice requires integration of the research evidence together with individual experience, including child and family history and preferences. Our goal, nevertheless, is to facilitate evidence-based policy and practice by making summaries of the best research evidence available to everyone concerned with improving children's mental health in BC.

### **EXECUTIVE SUMMARY**

Obsessive-compulsive disorder (OCD) is a disruptive and persistent mental disorder. Children with OCD may experience unwanted recurring thoughts or images (obsessions) and/or may engage in unnecessary repetitive behaviours (compulsions). Obsessions and compulsions interfere with daily activities and impair functioning in multiple domains in a child's life. As many as 2,000 children in BC may be affected by this condition. This report focuses on treating childhood OCD. Using systematic review methods, we identified the best available research evidence published over the past 10 years. To be included, studies had to meet a high standard involving randomization, use of comparison groups, a maximum drop-out rate of 20 per cent at post-test, and evidence of both clinical and statistical beneficial effects in populations similar to BC's.

#### **Findings**

Five articles on the treatment of childhood OCD met criteria. Articles examined the efficacy of cognitive-behavioural therapy (CBT) including exposure and response prevention (E/RP), medications and immunomodulatory treatments.

#### Recommendations

- The use of CBT including E/RP is supported by the research evidence and should be the first-line intervention for treating children with mild to moderate OCD symptoms. CBT and E/RP can be delivered in group and individual formats and should involve families whenever possible.
- Although serotonergic antidepressant medications have been found to reduce symptoms, given safety concerns, these medications should be reserved for more severe childhood OCD. If used, medications should be combined with psychological treatments such as CBT. It is essential to carefully monitor children being treated with medications.
- Immunomodulatory treatments have been found to reduce symptoms in some children with streptococcal infection-triggered OCD. However because these procedures are invasive, they should be reserved for severe cases of childhood OCD where there is a clear link with streptococcal infection, and where specialized assessment and treatment are available.
- Approaches that are not supported by the best available research evidence should be carefully evaluated or discouraged. For populations where the research evidence is lacking (such as children with concurrent mental health problems), interventions should be modelled after the principles and key elements of those approaches that are supported by research, and should also be evaluated.

### 1.1 What is Obsessive-Compulsive Disorder?

Children with obsessive-compulsive disorder (OCD) experience unwanted recurring thoughts or images (obsessions) and/or engage in unnecessary repetitive behaviours (compulsions) that disrupt daily activities. The most common obsessions are fear of contamination, fear of harming oneself or others, fear of family catastrophe or pre-occupations with order or exactness.<sup>14,15</sup> Compulsive behaviors are undertaken to resist, reduce or remove the obsessions in an effort to relieve the associated anxiety. The most common compulsions involve washing, cleaning and checking.<sup>16</sup> These repetitive behaviors often require considerable effort and time, and may be hidden from families and friends due to a sense of embarrassment. Consequently, symptoms may not be recognized until they are severe enough to interfere with family functioning, peer relationships and school performance.<sup>16</sup>

To be diagnosed with OCD, as defined in the Diagnostic and Statistical Manual of the American Psychiatric Association, a child must experience persistent obsessions, persistent compulsions or both.<sup>17</sup> These obsessions or compulsions must also cause significant impairment in functioning (for a detailed description see Appendix A). OCD is usually characterized by an understanding that the fears and accompanying behaviours are excessive or unreasonable. However, children are less likely to have insight regarding the irrationality of their OCD symptoms than adults and therefore, OCD symptoms may go unrecognized for significant periods of time. There are no definitive biological or psychological tests for OCD. Consequently, diagnoses must be made clinically based on reports from multiple informants (children, parents, teachers and others), ideally involving multidisciplinary team assessment.

Large-scale community-based epidemiological surveys in the UK and the US estimate that the prevalence rate for OCD is 0.2 per cent.<sup>1</sup> BC has a population of approximately one million children.<sup>18</sup> Based on these figures, as many as 2,000 children in BC may be affected. Concurrent mental health problems such as generalized anxiety, depression, tic disorders and specific developmental disabilities are common and add to children's distress and impairment.<sup>19</sup> Over 50 per cent of individuals diagnosed with OCD experience onset in childhood.<sup>16</sup> Among children, the peak age of onset is approximately 10 years old and during this prepubertal stage boys and girls are almost equally affected. However, for reasons that remain unclear, by later adolescence most individuals diagnosed with this disorder are young women.<sup>19</sup> Given the severe impairment caused by obsessions and compulsions and the chronic nature of these symptoms, the social costs associated with OCD are high. Moreover, because a large number of cases begin during childhood, it is essential to identify effective treatments for OCD in children to reduce symptoms and impairment early in life.

Children's mental health is determined by multiple biological, psychological and social factors that interact over time as a child develops. While it is not known what causes OCD, research to date has suggested biological origins.<sup>19</sup> Investigations that examine the relationship between OCD and the brain have identified possible links to impaired functioning in the frontal cortex (involved with executive functions such as memory and attention) and the basal ganglia (involved with motor control).<sup>20</sup> The possibility of a causal relationship between OCD and brain function is further strengthened by evidence in children who abruptly develop OCD or tic disorders after streptococcal infections. Referred to as PANDAS (for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection), work to date has suggested that in some cases the abrupt onset of OCD is due to changes in the basal ganglia caused by streptococcal infection.<sup>21</sup> However, only a small number of children appear to develop OCD from these autoimmune mechanisms. Given the complexity of mental disorders in children, notions of causation must also take into account the way that environmental factors can interact with biology over time as children develop. For example, families of children with OCD sometimes accommodate a child's obsessive-compulsive demands to avoid anxious or angry outbursts that can occur if a child's demands are not met.<sup>22</sup> Further, OCD symptoms are responsive to psychological treatments which teach children to "unlearn" ritualistic responses to anxious feelings, suggesting a social or psychological component to caussation.<sup>23</sup>

#### 1.2 Purpose of this Report

This report was requested by MCFD in order to inform the development of more effective policies and programs for treating children with OCD. Several recent reviews and guidelines have examined the treatment of OCD in children. One review by Geller and colleagues was systematic.<sup>19</sup> However, most of the literature that was included in this review was published prior to 1994. In addition, while other reviews were more recent, they were either not systematic<sup>14,23</sup> or they focused too narrowly on certain treatment approaches (such as medication).<sup>24,25</sup> Therefore, in order to summarize current research studies in a comprehensive way we have systematically reviewed the research evidence on the treatment of OCD in children published between 1994-2004.

The provision of effective mental health treatment involves a number of factors beyond research evidence. For instance, a practitioner's skills and style are critical to the success of any intervention including the ability to establish therapeutic relationships with children and families. These and other aspects of the therapeutic process including setting, frequency and milieu are generally referred to as non-specific factors. Specific factors are those that reflect the content or therapeutic approach, such as cognitive-behavioural therapy (CBT). Both specific and non-specific factors are essential to successful outcomes. However, this report addresses only the specific factors, or the content, that can be used in treating OCD. A discussion about the processes used to implement these interventions is beyond the scope of this report.

# **2** метноds

Using Medline, PsycINFO and the Cochrane Database of Systematic Reviews, we searched for studies published from 1994-2004 on treating OCD in children aged zero to 18 years. Studies were included that examined efficacy (can this intervention work in ideal settings?) and, if possible, effectiveness (does this intervention work in usual settings?). We also sought information on the costs of interventions. The search terms were *obsessive-compulsive disorder* combined with *treatment, management, intervention* or *therapy*. Where applicable, search terms were modified to follow database indexing. We also searched for reviews on the treatment of OCD in children. Reviews were then hand-searched to identify additional studies. All abstracts identified through these searches were assessed. Relevant study articles were then retrieved. Two reviewers independently assessed all articles retrieved using the criteria outlined in Appendix B. To be included, studies had to meet a high standard involving randomization, use of comparison groups, a maximum drop-out rate of 20 per cent at post-test, and evidence of both clinically and statistically significant beneficial outcomes in populations similar to BC's. For studies of medications, we also required double blinding and placebo controls. All populations met standard diagnostic criteria for OCD.<sup>17</sup> Disagreements about which articles to include were resolved by consensus between the first two authors. Findings were then summarized according to intervention type.

# **3** FINDINGS

In total, 22 articles were retrieved. Of these, five met criteria for inclusion in our review. Results are summarized in Table 1. All interventions demonstrated clinically and statistically significant reductions in symptoms related to OCD. Sample sizes ranged from 23 to 187. Two studies were placebo-controlled medication studies,<sup>26,27</sup> one study compared a psychological intervention to a waitlist control group<sup>22</sup> and two studies directly compared psychological interventions and medications.<sup>26,29</sup> Boys and girls were equally represented in most studies. Only one study documented the ethnicity of participants, reporting a Caucasian majority (92%).<sup>29</sup> Three studies were conducted in the US,<sup>26,27,29</sup> one in Australia<sup>22</sup> and one in the Netherlands.<sup>28</sup> Two studies included follow-up measures beyond the immediate post-treatment period. One assessed participants at six months<sup>22</sup> and the other at one year after treatment.<sup>26</sup> All were efficacy studies and none assessed costs.

Support was found for the efficacy of CBT.<sup>22</sup> CBT used cognitive-behavioural strategies including exposure response prevention (E/RP) with children and also involved parent skills training. E/RP involves exposing a child to a feared situation while the child refrains from engaging in anxiety reducing rituals. For example, a child who engages in excessive washing rituals would be gradually exposed to the anxiety-provoking situation (for example, touching dirt) while "unlearning" rituals by being prevented from engaging in handwashing or other cleaning behaviours. E/RP techniques are often paired with other cognitive-behavioural strategies such as cognitive restructuring (for example, teaching a child self-talk statements to "boss back" OCD) and relaxation training. The parent skills training component of the intervention included psychoeducation, problem-solving skills and strategies to reduce parental involvement in the child's symptoms.<sup>22</sup>

Additional support was found for the use of CBT in the treatment of childhood OCD. de Hann and colleagues found that E/RP in combination with other cognitive-behavioural techniques such as challenging the accuracy of obsessions and family support was more efficacious than the medication clomipramine.<sup>28</sup> Clomipramine, a tricyclic antidepressant (TCA), is an older medication thought to influence mood by increasing the availability of key neurotransmitters. The efficacy of clomipramine for reducing obsessive-compulsive symptoms was established in earlier studies (published prior to 1994).<sup>19</sup> However, the use of TCAs to treat other childhood mental disorders (such as depression) has been discouraged because of safety concerns.<sup>30</sup> Therefore, TCAs are generally not recommended for use in children except in treating severe cases of OCD when psychological treatment and other empirically-supported medications (such as serotonergic antidepressants) have not been successful.

Support was also found for the efficacy of one antidepressant medication. March and colleagues established that sertraline, a selective serotonin re-uptake inhibitor (SSRI), reduced obsessive-compulsive symptoms in children.<sup>27</sup> In another study, a combination of sertraline and CBT (including E/RP) was found to be more efficacious than either CBT or medication alone.<sup>29</sup> However, all three treatments (CBT alone, medication alone and the combination) did reduce obsessive-compulsive symptoms compared to a pill placebo.<sup>29</sup>

Although sertraline was efficacious, it was also associated with significant side effects including insomnia, nausea, agitation and tremors.<sup>27,29</sup>

Finally, researchers have examined immunomodulatory treatments for children with infection-triggered OCD. Immunomodulatory treatments interrupt the autoimmune processes that lead to swelling in the central nervous system (particularly in the basal ganglia) caused by the body's reaction to infection.<sup>26</sup> Perlmutter and colleagues restricted participation to children in which there was evidence of an association between OCD symptoms and a streptococcal infection, such as the presence of streptococcal antibodies.<sup>26</sup> Two immunomodulatory treatments were tested. Intravenous immunoglobulin (IVIG) therapy involved adding proteins (e.g., immunoglobulins) to the blood to boost the immune system. Plasma exchange (PE) was used to separate blood into different components and replace plasma, the liquid component of blood, with new fluid to support circulation, also boosting the immune system.<sup>26</sup> Although both of these treatments were efficacious compared to placebo, they were also associated with side effects such as nausea and headaches, and were time-consuming and invasive as both involved puncturing veins in the child's arm. Immunomodulatory treatments required specialized assessment and treatment teams, usually based in hospital settings.

### TABLE 1. Preventing Eating Disorders in Children

Treatment	Sample	Description	Main Findings
Cognitive-Behavioural Therapy (CBT) (Australia) <sup>22</sup>	<ul> <li>Focus: Children with OCD</li> <li>Age: 7-17 years</li> <li>Sex: 49% male</li> <li>Sample size: 77</li> </ul>	<ul> <li>Group &amp; individual CBT, including exposure &amp; response prevention, compared to waitlist controls over 14 weeks</li> <li>Weekly sessions plus 2 booster sessions (1 &amp; 3 months after treatment)</li> <li>Included structured parent &amp; sibling components</li> </ul>	<ul> <li>Improvements in obsessive- compulsive symptoms for CBT</li> <li>Similar gains found in individual &amp; group formats</li> <li>Effects maintained at 6-month follow-up</li> </ul>
Exposure & Response Prevention (E/RP) (Netherlands) <sup>28</sup>	<ul> <li>Focus: Children with OCD</li> <li>Age: 8-18 years</li> <li>Sex: 50% male</li> <li>Sample Size: 23</li> </ul>	<ul> <li>Individual E/RP compared to clomipramine over 12 weeks</li> <li>Weekly E/RP sessions included family support</li> <li>Maximum dose of clomipramine 200 mg/day</li> </ul>	<ul> <li>Improvements in obsessive- compulsive symptoms for E /RP &amp; clomipramine but E/RP was more efficacious</li> <li>Clomipramine associated with numerous side effects</li> <li>No follow-up</li> </ul>
Sertraline (US) <sup>27</sup>	<ul> <li>Focus: Children with OCD</li> <li>Age: 6-17 years</li> <li>Sex: Not reported</li> <li>Sample size: 189</li> </ul>	<ul> <li>Sertraline compared to placebo over 12 weeks</li> <li>Maximum dose of sertraline 200 mg/day</li> </ul>	<ul> <li>Improvements in obsessive- compulsive symptoms for sertraline</li> <li>Significantly more insomnia, nausea, agitation &amp; tremors in sertraline group</li> <li>No follow-up</li> </ul>
Sertraline with CBT <sup>29</sup>	<ul> <li>Focus: Children with OCD</li> <li>Age: 7-17 years</li> <li>Sex: 50% male</li> <li>Sample size: 112</li> </ul>	<ul> <li>Sertraline combined with CBT compared to CBT alone, sertraline alone &amp; placebo</li> <li>Weekly individual sessions included E/RP &amp; family support</li> <li>Maximum dose of sertraline 200 mg/day</li> </ul>	<ul> <li>Improvements in obsessive- compulsive symptoms for all treatments compared to placebo</li> <li>Combined treatment was more efficacious than CBT or sertraline alone</li> <li>No follow-up</li> </ul>
Immuno-modulatory Treatments (US) <sup>26</sup>	<ul> <li>Focus: Children with infection-triggered OCD or tic disorders</li> <li>Age: 5-14 years</li> <li>Sex: 63% male</li> <li>Sample size: 30</li> </ul>	<ul> <li>Intravenous immunoglobulin (IVIG) &amp; plasma exchange (PE) compared to placebo</li> <li>2-day intervention for IVIG &amp; 10-12-days for PE &amp; placebo</li> <li>Conducted in hospital settings</li> </ul>	<ul> <li>Improvements in obsessive- compulsive symptoms for IVIG &amp; PE</li> <li>Frequent reports of nausea, headache &amp; vomiting in both IVIG &amp; PE groups but side effects better tolerated by PE group</li> <li>Effects maintained at 1-year follow-up</li> </ul>

## **4** discussion

Overall, our review found five high quality studies published in the past 10 years on the treatment of childhood OCD. These studies examined CBT (including E/RP), antidepressant medications and immunodulatory treatments. All studies demonstrated efficacy, but none assessed effectiveness or costs. Given that only a small number of current, high-quality randomized controlled trials (RCTs) were available, this discussion will also draw on conclusions from four recent literature reviews written by experts in the field.

In spite of the limited number of studies reviewed, strong evidence was found supporting the use of psychological treatments for childhood OCD. Specifically, three RCTs demonstrated the efficacy of using CBT.<sup>22,28,29</sup> E/RP is an effective CBT technique common to all three studies. CBT was found to be effective in both group and individual formats.<sup>22</sup> Family participation was also found to be helpful in encouraging children and promoting improvements.<sup>22</sup> In addition to these RCTs, there are a large number of non-randomized, uncontrolled studies available on psychological treatments for childhood OCD. March and colleagues have recently summarized this research evidence and advocate for psychological treatments as first-line interventions, especially for children with mild to moderate symptoms.<sup>23</sup> Recommendations include pairing graduated E/RP with other cognitive-behavioural strategies (such as relaxation training) and encouraging family involvement. The American Academy of Child and Adolescent Psychiatry's practice parameters also promotes the use of psychological treatments as first-line interventions because they are safe and have long-lasting effects.<sup>14</sup>

Evidence was also found to support the use of one medication for the treatment of childhood OCD. Two RCTs supported the efficacy of the SSRI sertraline;<sup>27,29</sup> however, in one study sertraline was found to be more efficacious when used in combination with CBT than when used alone.<sup>29</sup> A recent meta-analysis by Geller and colleagues supports the efficacy of SSRIs in comparison to a placebo for reducing obsessive-compulsive symptoms in children.<sup>24</sup> However, the authors caution that SSRIs were associated with frequent side effects and that, in general, the effect sizes for these medications were only modest.<sup>24</sup> Moreover, concerns have been raised at an international level regarding the use of SSRI medications in children.<sup>31,32</sup> As a result, Health Canada has recently issued an advisory to warn practitioners that children taking these drugs may experience behavioural and emotional changes that increase the risk of harm to self or others.<sup>33</sup> Given the small therapeutic benefit and the possibility of significant side effects, medications should be reserved for more severe cases of OCD where psychological treatments cannot be used or have been unsuccessful. When medications are used, careful monitoring is essential.

For a subgroup of children with streptococcal-triggered OCD, immunomodulatory treatments have been found to be effective forms of treatment.<sup>26</sup> Specifically, both IVIG and PE improved obsessive-compulsive symptoms and these gains were maintained for up to one year. However, because both therapies are associated with side effects and the procedures are quite invasive, the use of immunomodulatory treatments should be reserved for severe, infection-triggered OCD where psychological interventions have not been successful, and where specialized assessment and treatment are available, usually in hospital settings.

There are several limitations in the treatment research. We found only five RCTs that met our criteria. More high quality studies need to be conducted on the treatment of childhood OCD. As well, most studies we reviewed did not assess concurrent disorders. Since concurrent mental health problems are common for children diagnosed with OCD, more research addressing treatment options for this population is required. While our review focused on treatment only, new research is also needed on preventing OCD. Finally, although the five RCTs did assess efficacy, none assessed effectiveness or cost.

Despite the limitations, new policies and programs need to be informed by the research evidence. Based on the research currently available, CBT that includes E/RP is a safe and efficacious treatment for mild to moderate childhood OCD. CBT and E/RP can be delivered in both individual and group formats and should involve families whenever possible. Use of other psychological treatments should be discouraged in the face of strong evidence supporting the use of CBT and E/RP. Medications were generally found to produce modest effects and were associated with significant side effects. However, the use of SSRIs such as sertraline may be considered in cases of severe OCD where empirically supported psychological treatments and medication may be the best option. The use of medications in children must be closely monitored. Finally, in severe cases of streptococcal infection-triggered OCD immunomodulatory treatments may be used where specialized assessment and treatment are available. Evaluation of all new programs designed to treat childhood OCD is imperative and would make a valuable contribution to both research and policy development in Canada.

## **5** RECOMMENDATIONS

- The use of CBT including E/RP is supported by the research evidence and should be the first-line intervention for treating children with mild to moderate OCD symptoms. CBT and E/RP can be delivered in group and individual formats and should involve families whenever possible.
- Although serotonergic antidepressant medications have been found to reduce symptoms, given safety concerns, these medications should be reserved for more severe childhood OCD. If used, medications should be combined with psychological treatments such as CBT. It is essential to carefully monitor children being treated with medications.
- Immunomodulatory treatments have been found to reduce symptoms in some children with streptococcal infection-triggered OCD. However because these procedures are invasive, they should be reserved for severe cases of childhood OCD where there is a clear link with streptococcal infection, and where specialized assessment and treatment are available.
- Approaches that are not supported by the best available research evidence should be carefully evaluated or discouraged. For populations where the research evidence is lacking (such as children with concurrent mental health problems), interventions should be modelled after the principles and key elements of those approaches that are supported by research, and should also be evaluated.

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### Features of Obsessive-Compulsive Disorder in Children

The following description is adapted from the *Diagnostic and Statistical Manual of the American Psychiatry Association* (4th Edition).<sup>17</sup> For a diagnosis of obsessive-compulsive disorder, a child must be under 18 years of age and must have recurrent obsessions and/or compulsions (as defined below) that cause considerable distress. The obsessions or compulsions must also be time consuming and must significantly impair functioning at home, at school, with peers or in the community.

**Obsessions** are intrusive or inappropriate thoughts or images that a child attempts to ignore or neutralize with some other thought or action (i.e., compulsions). Obsessions must be more than excessive worrying about real life problems and the child should recognize that the obsessions are produced by his or her own mind. Common obsessions include:

- Fear of contamination
- Fear of harming oneself or others
- Preoccupations with order or exactness
- Preoccupations with somatic, religious and sexual concerns

**Compulsions** are repetitive behaviours that a child feels compelled to act out in response to obsessions or to internally created rules. Although children use compulsions to try and reduce distress, these acts are either excessive or are not realistically connected to what they are supposed to neutralize. Common compulsions include:

- Washing or cleaning
- Repeating
- Checking
- Ordering or arranging
- Counting
- Hoarding

# B APPENDIX B

### Criteria for Assessing Research Articles\*

#### **Basic Criteria**

- Articles published in English about children aged 18 years or younger
- Articles on topics relevant to children's mental health policy and practice

#### Systematic Reviews

- Clear statement of relevant topic
- Clear description of the methods including sources for identifying literature reviewed
- Explicit statement of criteria used for selecting articles for detailed review
- At least two studies reviewed meet criteria for assessing original research studies

#### **Original Research Studies**

- Clear descriptions of participant characteristics, study settings and interventions
- Random allocation of participants to comparison groups
- Maximum drop-out rate of 20% (post-test)
- Outcome measures of both clinical and statistical significance
- For treatment, diagnostic "gold" standards used
- For medication, double-blinding, placebo-controlled procedures used

\*Adapted from Evidence Based Mental Health<sup>32</sup>